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# Parental Wellbeing Factors In Parents of Children with an Intellectual and Developmental Disability: A Research Portfolio

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*at the University of Edinburgh*

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**Signature** …Fiona McCrohan…… **Date** 30/4/15

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## Thesis Portfolio Outline

This thesis portfolio is divided into two main sections; chapter one and chapter two. Chapter one consists of a systematic review of the literature on mindfulness-based interventions for parents of children with intellectual and developmental disabilities. All the reviewed studies have been undertaken in the previous six years, and are reviewed in the context of previous intellectual disability research and following pre-defined quality criteria based on the York's University's Centre for Reviews and Dissemination (CRD, 2009). This systematic review adheres to the author guidelines issued for Journal of Applied Research in Intellectual Disabilities (Appendix 1). A reference list is provided at the end of this chapter which contains all of the references cited within the systematic review.

Chapter two consists of a journal article focusing on the role and relationship of parental variables (parental locus of control, employment, marital status, parent age) and child variables (child compliant and social behaviour, child problem behaviour, child diagnosis, level of learning disability, and child age). The role of the individual sub-domains of parental locus of control is further explored and discussed. This chapter adheres to author guidelines issued for the American Association on Intellectual and Developmental Disabilities (Appendix 2). A reference list is provided at the end of this chapter, which contains the references cited within the journal article.

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## Word Counts

| | |
|---|---|
| Systematic Review | 7,417 |
| Journal Article | 5,963 |
| Total Thesis Portfolio | 13,747 |

## Portfolio Thesis Abstract

*Aims*: Parents of children with intellectual and developmental disabilities tend to illustrate and report higher levels of stress and lower wellbeing than parents of typically developing children. This thesis aimed to explore the aspects of this relationship between parental wellbeing and raising a child with heterogeneous intellectual and developmental disability. Firstly, the thesis aimed to review the current literature and evidence base for mindfulness-based group and individual interventions and their effect on psychological outcomes for parents of children with intellectual and developmental disabilities. Secondly, a research study aimed to explore the role of overall parental locus of control and particular sub-domains of locus of control on parent reported wellbeing. Furthermore, the role of child compliant and social behaviour, child problem behaviour, diagnostic groups, level of functioning, and demographic variables were explored.

*Method*: A systematic review of the literature was conducted to address the first aim of this thesis. Within the research study, a single sample of parents and family carers ($n$ = 114) completed an online anonymous survey consisting of demographic information and three self-report measures; a modified version of the Parental Locus of Control Scale, the Warwick-Edinburgh Mental Wellbeing Scale, and the Nisonger Child Behaviour Rating Form.

*Results*: The systematic review illustrated that mindfulness-based interventions appear to have a significant effect on a number of parent psychological outcomes; such as wellbeing, stress, mental health, compassion, and mindfulness. A further four papers indicated a significant impact on child behavioural outcomes from parental mindfulness interventions. The research study indicated parental locus of control, in particular the two sub-domains of child control, and parent efficacy significantly mediated the relationship between child problem behaviour and parental wellbeing.

*Conclusions*: There is a need to further explore the effectiveness of mindfulness interventions on parental distress and child behaviour, in particular in comparison to well-established interventions and groups. The research study results highlight the importance of parental attributions in influencing the wellbeing of parents of children with intellectual and developmental disabilities. However, it is clear from these findings that there is a complex relationship between parent cognitive attributions and broader social and societal factors. These findings may inform future practice with these families, although further research to explore these complex relationships is required.

**Keywords:** intellectual, developmental, disability, parent, wellbeing, stress, coping.

## Chapter 1: Systematic Review

# The effect of mindfulness-based interventions on psychological outcomes of parents of children with intellectual disability and developmental disability: A systematic Review


## Abstract

*Background:* Parents of children with disabilities tend to show higher levels of stress, depression and anxiety than parents of healthy or typically developing children. There is growing interest in applying mindfulness-based interventions to parents of children with intellectual or developmental disabilities. This paper aimed to review the growing area of mindfulness-based interventions for these parents.

*Methods:* Online database searches led to identification of nine papers eligible for review. These were assessed against predefined criteria and the findings were synthesised.

*Results:* Eight of the nine papers highlighted that individual or group MT significantly affected parental psychological outcomes. Three papers indicated that mindfulness interventions had an indirect effect on child behaviour.

*Conclusions:* There is a need to further explore the effectiveness of particular mindfulness interventions on parental distress and child behaviour and to enable the development of an evidence base that will inform future service interventions and treatment guidelines.



**Keywords:** disability, intellectual, developmental, mindfulness, intervention, parent

## 1. Introduction

There is a substantial research base outlining that parents of children with disabilities tend to show higher levels of stress, depression and anxiety than parents of healthy or typically developing children (e.g Baker *et al*. 2002; Beckman 1991; Emerson 2003; Yamada *et al*. 2007). Parenting a child with disabilities is associated with lower overall wellbeing (Edwards & Titman 2010), and can lead to increased psychological, physical, and economic problems (Kilic *et al*. 2013). These may arise due to increased burdens on parents from both a practical point of view (e.g. treatment, medicine, or care regimes), an emotional point of view (e.g. feelings of worry, guilt, or failure), or a combination of both (McCann *et al*. 2012; Wallander & Varni 1998). These factors and their psychological implications have been shown to occur across diagnoses or syndromes of intellectual disability (Foster *et al*. 2010; Stein & Jessop 1989), developmental disabilities (Hastings *et al*. 2005; Singer 2006), and behavioural difficulties (Baker *et al*. 2002; Neece *et al.* 2012). In addition to the direct impact of increased burden of daily living, parents and carers may experience further indirect impacts on relationships with partners or family members (Kilic *et al*. 2013), and wider social networks, career prospects, and their own physical health (Davis *et al*. 2008; Wallander & Varni 1998). In the UK it is estimated that most individual family carers spend over fifty hours weekly carrying out their caring responsibilities (Cairns *et al*. 2014), which affects parents' ability to maintain and attend to their other life-roles. These increased burdens and stress tend to be cumulative and persist over time (Glidden & Schoolcraft 2003), and both physical and mental health are both likely to deteriorate further the longer an individual has been a carer (Carers UK 2012).

Many parents and families adjust and manage these stressors (Goodley & Tregaskis 2006), describe parenting a child with disabilities as both challenging and rewarding (Nurallah 2013), and view their child as a positive contributor to family life (Behr & Murphy 1993; King *et al*. 2006). There is, however, substantial variance in individuals' adaption to this life role. Furthermore, some parents use coping strategies which initially reduce anxiety but may not be helpful in the long term; for example, denial and planning may over time increase symptoms of depression and decrease parental self-efficacy (Woodman & Hauser-Cram 2013). Coping has been investigated in several areas of research and acceptance and adjustment have been shown to be important factors in successful coping within acute (Kohl *et* al. 2013) and chronic pain (Esteve *et* al. 2007; McCracken & Eccleston 2003; McCracken *et al.* 2005), depression and anxiety (Powers *et al.* 2009). Interventions incorporating these concepts of acceptance, active coping, adjustment, and emotional tolerance have been developed for use with many population groups as part of the 'third-wave' cognitive behavioural interventions such as mindfulness-based interventions.

Mindfulness is described as the deliberate non-judgemental attention or acceptance of the present experience and ongoing non-judgemental acceptance and contact with psychological experience (Whittingham 2014). It involves focusing attention in a purposeful, non-judgemental, and non-reactive way on the present moment and what is happening the individual's mind, body, and surroundings (Kabat-Zinn 1990). As a concept, mindfulness has surged in popularity in the past decade, both in the popular press and in psychotherapy literature (Didonna 2009; Shapiro & Carlson 2009). This increased interest may be due to mindfulness approaches being viewed as an alternative or an addition to existing therapy programmes; mindfulness approaches differ from existing therapy programmes as mindfulness aims to improve acceptance of symptoms or situations that are difficult or impossible to change, focus on the present moment, and to enable and encourage the reflective capacity of individuals when viewing and responding to situations (Fjorback et al. 2011). Mindfulness is a core strategy within treatment packages such as Mindfulness-based Stress-Reduction (MBSR) (e.g. Kabat-Zinn 2003) and mindfulness-based cognitive therapy (MBCT) (Segal *et al*. 2002). MBSR is a structured group programme which consists of eight weekly extended 2-2.5-h sessions, daily homework, and a full day retreat towards the final weeks of intervention (Kabat-Zinn 1990). The programme focuses on developing mindfulness skills through formal practices (seated meditation, body scan, and mindful yoga or movement) and integrating these skills into daily life as a coping resource (Fjorback *et al*. 2011). Similarly, MBCT combines mindfulness training (MT) and practice with cognitive therapy over eight weekly 2-h sessions. This programme uses formal mindfulness practices, but it focuses more on cognitions, noticing these thoughts and identifying patterns (Fjorback *et al*. 2011). The emphasis is on changing the relationship to an individual's thoughts (Segal *et al*. 2002), which differs from the emphasis of cognitive behavioural therapy on challenging an individual's thoughts (Bennett-Levy 2003). Further approaches to psychotherapy which envelop mindfulness principles within largely frameworks of psychotherapeutic programmes have been developed including Acceptance and Commitment Therapy (ACT) (Hayes *et al*.1999) and Dialectical Behaviour Therapy (DBT) (Linehan 1993). These programmes are not considered in the current review due to the broader range of cognitive approaches used within these interventions.

There is evidence of the effectiveness of mindfulness-based approached in managing physical and psychological health problems in various clinical populations including stress, anxiety, depression, pain, sleep problems, and disordered eating (Baer 2003; Chiesa & Serretti 2010; Fjorback *et al*. 2011; Raes *et al*. 2009; Teixeira 2008; Winbush *et al.* 2007). Furthermore, research has indicated that mindfulness may promote positive skills such as self-control, objectivity, emotion tolerance (Bishop *et al*. 2004; Brown *et al*. 2007; Hargus *et al* 2010; Hayes & Feldman 2004; Leary & Tate 2007; Masicampo & Baumeister 2007; Shapiro *et al*. 2006), and the ability to relate to others and

one's self with kindness, acceptance, and compassion (Fulton 2005; Wallace 2001). More recently, there has been interest in applying mindfulness and mindfulness-based interventions to parents of children with disabilities, primarily parents of children with intellectual or developmental disabilities.

Parents have traditionally been offered three types of intervention; training skills groups or interventions, distress targeted psychological interventions, and family-wide practical supports (IASSIDD 2014). Although these groups are not directly targeting parental wellbeing, there is good evidence for skills groups indicating positive outcomes and improvement in parent's knowledge and ability in providing communication and social skills interventions for their children (Dawson *et al.* 2010; Diggle *et al*. 2003) with a small but positive secondary effect (Singer *et al.* 1999, 2007). Cognitive behavioural interventions may also reduce parent distress, although these interventions are more effective as a combined approach with skills training and practical or respite support (Singer *et al*. 2007). Building on these findings, mindfulness training or based interventions may help build both parent skills in actively reducing their own levels of stress, increase their knowledge insight into their wellbeing, and may further assist acceptance and adjustment, without judgement (Blackledge & Hayes 2006).

However, while efficacy data are important indicators and evaluations of treatments, this can be affected by the treatment approach, format and dosage of intervention, and fidelity to treatment programmes. Within psychosocial interventions, it is important to evaluate how well therapists adhere to the treatment protocol and how faithfully the intervention has been provided in order to truly assess the intervention's effect on the outcome of interest, it's comparative effectiveness, and distinguish between developmentally similar treatment programmes (Segal *et al*. 2002; Shaw *et al*., 1999). That is, in order to assess the true and replicable impact of an intervention, it must be faithful to the outlined or manualised and measured intervention. Similarly, the dosage of an intervention may significantly impact individual outcome; there is a positive relationship between the length of time or number of sessions spent in therapy and the amount of change and the individual outcome (Orlinsky *et al.* 1994; Steenbarger 1994; Hansen *et al*. 2002). The literature suggests that between 13 and 18 sessions are needed for 50% of patients to meet criteria for recovery (Anderson & Lambert 2001; Hansen *et al*. 2002), and this effect tends to level with diminishing gains, particularly in terms of symptoms of distress, with the exception of skills practice (Barkham *et al*. 1996; Hansen *et al.* 1998; Kopta *et al.* 1994).

Lastly, the format of the intervention; through group or individual intervention, can significantly

impact outcomes. Patients often attribute their improvement to group factors (Burlingame *et al*. 2011; Yalom & Leszcz, 2005), and it thought that the mechanisms for change within group interventions may differ from individual interventions (Cruwys *et al*. 2015). For example; group cohesion and bonding with individuals with similar experiences (Cruwys *et al*. 2014; Hornsey *et al*. 2009), the effect of normalising difficulties and experiences within a group and increased feeling of not being alone and other parents experience similar difficulties (Brabender *et al.* 2004; Yalom & Leszcz, 2005) may affect outcomes of group interventions. Similarly, it is thought that normative social influence, where individuals modify their behaviour and attitudes in order to conform to group norms may play a role within group interventions (Cruwys *et al*. 2015) with an opportunity for enhanced social support (Renjilian *et al*. 2001). However, there is some suggestion that there is a less clear effect of cognitive change processes within group interventions than individual intervention (Longmore & Worrell 2007, Oei *et al*. 2014), and the reduction of the factors of bonding, normalising, and normative social influence over time.

The current review aims to explore added benefit of providing mindfully-based interventions to parents and families of a child with ID or DD. Due to the recent surge of research in the use of mindfulness-based approaches to decrease psychological distress experienced by parents of children with a developmental or learning disability, a review of the current literature base in this growing area is both timely and of clinical relevance. This paper aimed to review the growing area of mindfulness-based interventions for parents of children with additional needs, specifically intellectual or developmental disabilities.

### *1.1 Aims of the Review*

The current review aimed to identify and critically appraise the research literature and synthesise the findings and conclusions of these studies in order to provide a useful and encompassing overview of the relationship between mindfulness-based interventions and parental psychological outcomes in parents of children with an intellectual or developmental disability.

## 2. Method

### *2.1 Protocol*

A selection protocol was developed prior to the literature search to guide the search and paper eligibility decision making processes. This comprised an outline of the review question, eligibility criteria, population of interest, outcomes of interest, planned search strategy, planned data extraction, quality assessment methods, and the intended method of synthesising and disseminating the findings. As suggested in guidance for undertaking reviews in healthcare produced by York's University's Centre for Reviews and Dissemination (CRD 2009), the protocol predefined the method and the scope of the current systematic review, with the aim of minimising bias and facilitating transparency. The systematic review protocol is provided in Appendix 3.

### *2.2 Eligibility Criteria*

Due the relatively limited literature available in the area under review, it was decided to include unpublished studies as well as published studies with or without control groups, individual case studies, quasi-experimental, and observational studies in the literature search. No date restrictions were used in this review; however, as this is a newly developing field of research, much of the research has occurred in recent years. The current review focused on a particular population, therefore only studies which included parents or family caregivers of children with a disability were considered. Within this review a disability was considered to be an intellectual disability, developmental disability or disorder (e.g. Autism), or a genetic syndrome or disorder which is associated with intellectual disability (e.g. Down syndrome, Cri du Chat, Angelman syndrome). Studies were included in the review if they investigated mindfulness or mindfulness-based approaches as interventions and their effect on parental stress levels, psychological outcomes, and parent experience of parenting. The studies were deemed to have to measure at least one of the following psychological outcomes: wellbeing, adjustment, stress, mental health (e.g. depression or anxiety), and to have investigated the relationship between the MT and psychological outcomes.

### *2.3 Exclusion Criteria*

Studies where the full-text was unavailable were considered to not have enough information to allow for a quality analysis and therefore were excluded. Conference proceedings were excluded, as it would be difficult to appraise the studies based on this limited information. Alternative versions of abstracts and studies outlined in conference proceedings were sought through use of search engines and directly contacting the authors. Qualitative research was excluded as the review focused upon the relationships between specific variables. Studies where mindfulness interventions were conducted with individuals with intellectual disability, parents with intellectual disabilities, or in relation to aspects other than parenting a child with additional needs were excluded as these were outwith the focus of the current review.

**Table 1.1: Inclusion and Exclusion Criteria for Review**

| Inclusion Criteria | Exclusion Criteria |
|---|---|
| Published case studies, small studies, controlled or non-controlled studies | Duplicate records |
| Population sample of parents or family caregivers | Qualitative Research |
| Children had a physical, developmental, or intellectual disability or syndrome | Conference proceedings |
| Studies investigated mindfulness-based interventions for this population | Abstract/Full-texts unavailable |
| At least one of the following parent or family psychological outcomes were measured: stress, well-being, mental health (e.g. depression), or parental experience | Review Paper |
| Change in parent or family outcome(s) post MT explored | Studies which incorporate mindfulness and additional interventions; such as focusing on cognitions, beliefs, or intervening in problem areas (CBT, ACT) |
| | Studies focusing on Mindfulness-Based interventions for individuals with disabilities and paid carers of individuals |

### *2.4 Information Sources*

Systematic searches were carried out on OVID (incorporating Embase, Medline, Psycharticles, and Psychinfo), EBSCO (incorporating CINAHL+, ERIC, Medline, Psycharticles, and web of knowledge), and ASSIA online databases. All publication dates provided by these online databases were included, up until the date on which the search was conducted, 18th of November 2014.

### *2.5 Literature Search Strategy*

The search included a multi-database keyword search, individual database keyword search, and topic/heading searches. Variations of the following list were used: parent, mother, father, carer, disability, and mindfulness.

### *2.6 Study Selection*

The selection of eligible studies was carried using the inclusion and exclusion criteria, as outlined in Table 1.1. Abstracts of the identified studies were initially reviewed in order to determine their inclusion in the full-text review. The full-text articles which were deemed to meet eligibility criteria were then further reviewed. The studies which met the inclusion criteria after the second level of review were then selected to be part of the full final methodological review and appraisal stage. A flowchart based on the PRISMA statement (Moher *et al*. 2009) provides an overview of the systematic review study selection process and details each stage (Fig. 1.1).

### *2.7 Data Collection*

Information was collated for each of the studies included in the final selection. This included study characteristics, participant characteristics, outcome data, and results. A standardised form was developed and used in this process to maintain consistency throughout the review. A summary of this information is provided, see Table 1.2.

### *2.8 Assessment of methodological quality*

A quality assessment tool was developed for the purpose of assessing and appraising the methodological quality of the studies in the final review stage of the systematic review (see Appendix 4). This was based on existing guidelines outlined in York University's Centre for Reviews and Dissemination guidance for undertaking reviews in healthcare (CRD 2009).

### *2.9 Summary measures*

The selected studies were rated using ten quality criteria across six dimensions of quality: research question and objectives, population sampling, research design and method, statistical analysis, quality of reporting, and generalisability. These criteria were based on guidelines outlined in York University's Centre for Reviews and Dissemination guidance for undertaking reviews in healthcare (CRD 2009). Numerical ratings were given for each item using the following categories: 0 = not addressed/not reported/not applicable, 1 = poorly addressed, 2 = adequately covered, 3 = well covered. An item was rated as not applicable if it was not relevant to the study design or the research article. The total numerical scores were calculated for each study, which were then further converted into percentages. Studies which had items deemed not applicable were adjusted to reflect the correct number of items; such as the sample size within single cases studies. Percentages were categorised after all articles had been reviewed in order to provide an overall descriptive quality rating for each study (Good > 70%, fair > 50%, weak < 50%). A detailed breakdown of these measures and ratings for each study are provided in Table 1.3.

All studies included in the final selection for review were scored independently according to the assessment criteria by two researchers. Individual item ratings, subtotals for each domain, and overall scores for each study were assessed for inter-rater reliability. The Cohen's Kappa (Cohen 1960) was considered to indicate substantial agreement between raters at 0.72.

**Figure 1.1: Flowchart of Papers Identified and Excluded**

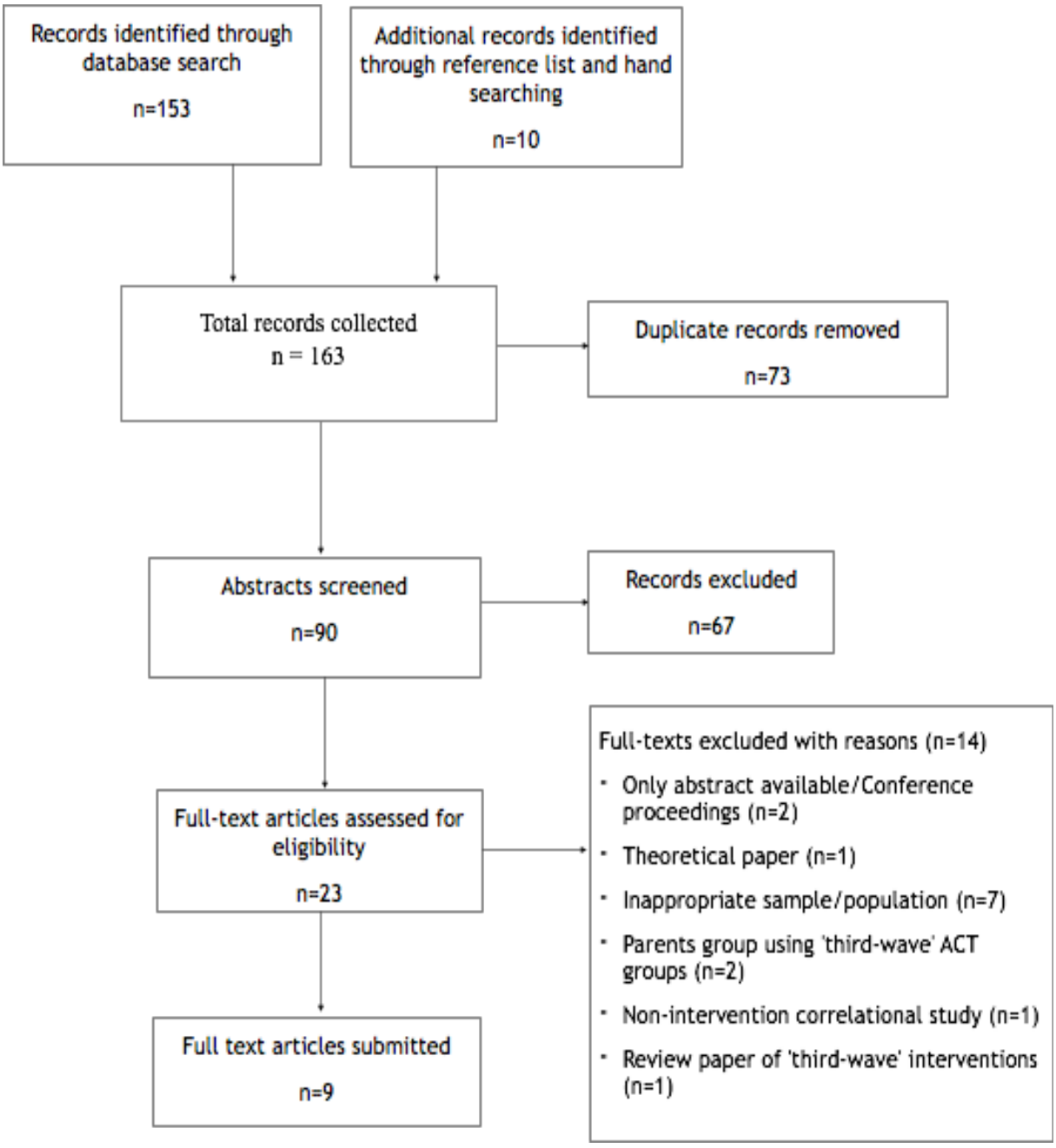

**Table 1.2: Summary of reviewed papers**

| Study | Country of origin | Design | n | Child Diagnosis[1] | Intervention Type | Intensity (total hours) and duration | Outcome measures[2] | Analyses | Limitations |
|---|---|---|---|---|---|---|---|---|---|
| Ferraiolo & Harris (2013) | USA | Randomised between-group design by intervention type | 15 | ASD, Asperger's syndrome, PDD-NOS | Mindfulness-based parent training group and skills-based parent training group | 16h - 8 weeks of 2h sessions | PSI-SF, GHQ, MAAS, ABA qre | *t* tests, means | Small sample size,under-powered stats,group variability |
| Neece (2014) | USA | Randomised waitlist control group, pre-post intervention measures | 46 | ASD | MBSR group intervention | 22h – 8 two-h weekly & 6h day retreat | PSI-SF, FIQ, CES-D, SWLS, CBCL, SUDS | t-tests, hier-archal linear modelling, chi-square model comparison test | Small sample size for controlled study, no active control group, no objective measures |
| Benn *et al.* (2012) | USA | Randomised waitlist-control group design, using repeated measures | 20 parents | ASD, ADD/ID, Cognitive impairment | Stress management and relaxation (MBSR plus emotion regulation & compassion focus) | 36h – 9 weeks of 2.5h & 2 full days | Mindfulness qre, PSS, STAI, CES-D, PANAS, PWBS, PSI, PSE | *t*-tests, ANCOVA, mediation analysis | No objective measures, no active control group, participant attrition |
| Bazzano et al. (2013) | USA | Repeated-measures pre-post intervention evaluation design | 66 | ASD, ID, Cerebral Palsy, Down Syndrome | Adapted MBSR group | 20h – 8 weekly 2h & 4h retreat | MAAS, PSS, Parental Stress Scale, PWBS, SCS | ANOVA, *t*- tests, correlations, multiple linear regression | Self-selected participants, no control group |

[1]*ASD* (Autism Spectrum Disorder), *PDD-NOS* (Pervasive Developmental Disorder – Not Otherwise Specified), *ADD* (Attention Deficit Disorder), *ID/LD* (Intellectual Disorder/Learning Disability), *DD* (Developmental Disorder), *MBSR* (Mindfulness-based Stress-Reduction).

| Study | Country of origin | Design | n | Child Diagnosis[1] | Intervention Type | Intensity (total hours) and duration | Outcome measures[2] | Analyses | Limitations |
|---|---|---|---|---|---|---|---|---|---|
| Singh et al. (2007) | USA | Small N design - multiple-baseline paired-samples comparison | 4 | Intellectual disability (ID), developmental disability (DD) | Individual MT and practice | 24h - 3 weekly spaced over 12 intermittent weeks, 52 week practice stage | Aggression & social interaction event recording, subjective units of interaction, parenting & mindfulness,PSI | Means, t-tests | Small sample size, no comparison groups/participants |
| Singh et al. (2006) | USA | Small N design - multiple-baseline paired-samples comparison | 3 | Intellectual disability (ID), developmental disability (DD) | Individual MT and practice | 24h - 3 weekly spaced over 12 intermittent weeks, 52 week practice stage | Event recording of aggression, non-compliance, & self-injury, subjective units of interaction, parenting & mindfulness | Mean comparison over time | Small sample size, lack of reliable statistics, lack of generalisability |
| Dykens et al. (2014) | USA | Randomised group design | 202 | ASD, Asperger's syndrome, genetic syndrome, PDD-NOS | MBSR group or Positive Adult Development group (control) | 9h – 6 weekly 1.5h sessions | BAI, PSI-SF, BDI, Insomnia severity index, PWBS, Life satisfaction scale | 2x2 ANOVAS, *t* tests, regression modeling | No randomised non-treatment control group, no objective measure |

| Study | Country of origin | Design | n | Child Diagnosis[1] | Intervention Type | Intensity (total hours) and duration | Outcome measures[2] | Analyses | Limitations |
|---|---|---|---|---|---|---|---|---|---|
| Singh et al. (2014) | USA | Small N design - multiple-baseline paired-samples comparison | 3 | ASD, Asperger's syndrome | Mindfulness-based Positive behaviour support - Individual MT and practice | 10h – Initial 2h session, further 8 weeks of 1h session, 48 week practice stage | Bx event recording of aggression, compliance, & disruptive behaviour, PSS | Repeated-measures ANOVA, qualitative interviews | Small sample size, lack of generalisability |
| Epstein (2009) | USA | Small N design - single subject multiple baselines comparison | 8 | ASD, Asperger's syndrome, Cornelia DeLange syndrome, PDD-NOS | MBSR group | 8h – 8 weekly 1h sessions | PSI, PLOC, AAQ-2, KIMS, Cortisol measurements | Inferential statistics comparison, auto-correlation | Small sample size, self-referred participants, lack of generalisability |

[2]*AAQ-2* (Action and Acceptance Questionnaire-2; Mccurry *et al*. 2004), *BAI* (Beck Anxiety Inventory; Beck & Steer 1990), *BDI* (Beck Depression Inventory; Beck *et al*. 1996), *CBCL* (Child Behaviour Checklist; Achenbach & Ruffle 2000), *CES-D* (Centre for Epidemiologic Studies Depression Scale; Radloff 1977), *FIQ* (Family Impact Questionnaire; Donenberg & Baker 1993), Five facet Mindfulness Questionnaire (Baer *et al*. 2006), *GHQ* (General Health Questionnaire; Goldberg 1978), *KIMS* (Kentucky Inventory of Mindfulness Skills; Baer *et al*. 2004), *MAAS* (Mindfulness Awareness Attention Scale; Brown & Ryan 2003), *PANAS* (Positive and Negative Affect Schedule; Watson *et al*. 1988), *PLOC* (Parental Locus of Control; Campis *et al*. 1986), *PSE* (Parenting Self-efficacy; Dunst & Masiello 2002), *PSI-SF* (Parenting Stress Index short-form; Abdin 1997), *PSS* (Parental Stress Scale; Berry & Jones 1995), *PSS-10* (Perceived Stress Scale-10; Cohen *et al.* 1983), *PWBS* (Psychological Well-being Scale; Ryff & Keyes 1995), *STAI* (State-Trait Anxiety Inventory; Kendall *et al.* 1976), *SUDS* (Subjective Units of Distress), *SWLS* (Satisfaction with Life Scale; Diener *et al*. 1985).

## 3. Results

### *3.1 Study Selection*

A total of 163 records were identified through the literature search; figures relating to reasons for exclusion are provided (Fig. 1.1). An overview of studies selected for inclusion in the systematic review is provided in Table 1.2, followed by a more in depth summary of findings relating to MTs for parents of children with disabilities and psychological outcomes.

### *3.2 Excluded Studies*

As Figure 1.1 shows, 154 studies were excluded from the review due to: duplication, inaccessibility, sample population, methods or design outside of the inclusion criteria and the scope of the review.

### *3.3 Included Studies*

As summarised in Table 1.2, nine quantitative studies undertaken between 2009- 2014, four of these studies within the previous two years, were selected for review. All of the reported studies were undertaken and completed in the United States. These studies included a total of 424 parents (354 mothers and 70 fathers) of children with intellectual or developmental disability, and genetic syndromes. In order to investigate the research question, all the studies focused on the effectiveness of MTs on parental psychological outcomes (stress, well-being, subjective parenting experience, and mental health).

Parental stress was the most studied psychological outcome. All nine studies included parental stress as an outcome variable; this was most commonly studied using the Parenting Stress Index (PSI; Abidin 1990) in six of the studies. Parental anxiety, depression, general distress, general mental health, acceptance and well-being were further studied as variables in eight of the studies. In terms of more global parent characteristics, experiences of parenting, parental locus of control, family impact, compassion, and parental coping were also explored in six studies. Child characteristics that were investigated included parent-child interaction, emotional and/or behaviour problems, developmental stage, adaptive function, and child characteristics associated with stress on the PSI. These child characteristics were examined in varying formats across all nine studies. Adaptability, family cohesion, and family impact of stress also studied, demographic characteristics were examined across all nine studies.

### *3.4 Methodological quality of Studies*

A summary of each paper's methodological ratings on each domain is provided in Table 1.3, in addition to total scores, percentage scores and corresponding methodological quality category descriptors. There were two primary study design types used within the nine papers: small-n studies and randomised group design studies. The papers were further reviewed in terms of their design.

**Table 1.3: Quality Review of Selected Papers**

| | | Dykens et al. (2014) | Singh et al. (2014) | Singh et al. (2006) | Singh et al. (2007) | Bazzano et al. (2013) | Benn et al. (2012) | Ferraioli & Harris (2013) | Neece (2014) | Epstein (2009) |
|---|---|---|---|---|---|---|---|---|---|---|
| Percentage and overall quality category | | 76.7<br>Good | 58.3<br>Fair | 44.4<br>Weak | 47.2<br>Weak | 82.0<br>Good | 79.48<br>Good | 61.5<br>Fair | 74.4<br>Good | 58.9<br>Fair |
| Total | max=39 | 30 | 21 | 16 | 17 | 32 | 31 | 24 | 29 | 23 |
| Overall method quality rating | max=3 | 3 | 2 | 1 | 2 | 3 | 3 | 2 | 2 | 1 |
| Generalisability | max=3 | 2 | 1 | 1 | 1 | 2 | 1 | 1 | 2 | 2 |
| Quality of reporting | max=3 | 3 | 2 | 2 | 2 | 2 | 3 | 2 | 2 | 1 |
| Statistical analysis | max=3 | 3 | 2 | 1 | 2 | 2 | 3 | 2 | 2 | 2 |
| Design and method | max=9 | 6 | 5 | 3 | 3 | 7 | 7 | 6 | 6 | 6 |
| Intervention appropriateness and fidelity | max=6 | 5 | 5 | 3 | 3 | 6 | 6 | 2 | 5 | 4 |
| Sampling | max=9 | 6 | 3 | 2 | 3 | 7 | 6 | 6 | 7 | 4 |
| Research questions and objectives | max=3 | 3 | 2 | 3 | 2 | 3 | 2 | 3 | 3 | 3 |

### *3.5 Research question and objectives*

All of the four randomised-groups and the pre-post design (Bazzano *et al.* 2013) papers were rated well for drawing on previous research and models of intervention to address a clear and focused research question. They all highlighted previous research outlining that parents of children with intellectual and developmental disabilities often report and experience higher levels of stress than parents of typically developing children (Baker *et al*. 2005; Emerson 2003; Webster *et al.* 2008). This high level of stress is often chronic and pervasive, and it is often shown to be linked to a variety of adverse physical and mental health outcomes (Emerson 2003; Schieve *et al.* 2007). Dykens *et al*. (2014) outlined that these higher levels of stress are predicted by economic hardships (Parrish *et al*. 2008), insufficient supports (Hassall *et al*. 2005) and difficulties such as child aggression, self-injury, and social or communicative difficulties (Dykens *et al*. 2000). Some of the studies further discussed the bi-directional relationship between child behaviour and parental stress (Baker *et al.* 2003; Keogh *et al*. 2000; Neece *et al*. 2012). Lastly, parental mental health or mental well-being was focused on by all the reviewed papers, which outlined the impact of increased parenting stress on both mothers and fathers and particularly their association with parent depression (e.g. Hastings *et al*. 2006), marital conflict (e.g. Kersh *et al*. 2006), poorer physical health (Eisenhower *et al*. 2009; Oelofsen & Richardson 2006), less effective parenting (e.g. Coldwell *et al*. 2006), and increased behaviour problems (e.g. Baker *et al*. 2003; Neece *et al*. 2012).

All nine studies contextualised the development of their research questions in previous research highlighting the increased demands on parents of children with developmental disabilities or intellectual disabilities and factors that have been associated with variation in parental psychological outcomes such as stress, overall distress, general mental health, well-being, anxiety and depression. These factors can be broadly summarised as child factors (behaviour problems, characteristics of the condition), parental factors (coping style, stress-management, self-esteem, and self-efficacy), and environmental factors (available services, social support systems).

### *3.6 Design and method*

A randomised group design was used in four of the studies reviewed. Two of the reviewed studies used active control groups using a behavioural skills group (Ferraioli & Harris 2013) and a positive adult development group (Dykens *et al.* 2014). A further two studies used a waitlist control group in comparison to the active MT group (Benn *et al.* 2012; Neece 2014). This design prevented the direct comparison of the effectiveness of a mindfulness intervention and an alternative intervention and therefore the usefulness of this intervention in services is difficult to establish. Finally, Bazzano *et al.* (2013) used a pre-post intervention design, which highlights similar difficulties in relation to

the conclusions that can be drawn from intervention studies using this design. That is, although this study can highlight the effectiveness of the group intervention within one or two successive groups, no conclusion can be abstracted as to the comparative effectiveness of the intervention against no treatment or an alternative treatment. The second most common design used within the reviewed studies was a small-n multiple-baseline design (Epstein 2009; Singh *et al*. 2014; Singh *et al*. 2007, Singh *et al*. 2006). Although these four studies provided great detail in the effect of the mindfulness intervention on the individual participants, it is difficult to generalise these findings beyond these participants.

### *3.7 Sampling and Measures*

The representativeness of the samples selected varied between studies; five of nine studies focused exclusively on mothers in their samples (Dykens *et al*. 2014; Singh *et al*. 2014; Singh *et al*. 2007; Singh *et al*. 2006) or had minimal male samples, such as two fathers in the total sample (Benn *et al*. 2012). One study focused exclusively on fathers in relation to their levels of stress and coping and the effectiveness of a mindfulness group intervention (Epstein 2009). In the remaining studies, the percentage of fathers included in the sample ranged from 21.7% (Neece 2014) to 23% (Bazzano *et al.* 2013) and 33% of the total sample (Ferraioli & Harris 2012). This low representation of fathers does not allow for reliable comparison between genders, and both the level of distress and parenting difficulties experienced by fathers of children with developmental or intellectual disabilities. Furthermore, the lack of a sufficient male sample in studies does not allow the study of the full effectiveness of a MT for both mothers and fathers and the differences that may exist between these groups. This reflects an ongoing difficulty in research with parents where fathers are under-represented (Phares *et al*. 2005).

Two of the randomised-group design studies (Dykens *et al*. 2014; Neece 2014) and the pre-post design study (Bazzano *et al*. 2013) had good sample sizes, ranging from 202 participants (Dykens *et al.* 2014) to smaller sample sizes of 46 (Neece 2014). However, a further two of the randomised-group design studies had much smaller sample sizes of 15 (Ferraioli & Harris 2013) and 20 participants (Benn *et al*. 2012). These smaller sample sizes indicated large numbers of parents who chose not to take part in the study and further attrition throughout the study (Ferraioli & Harris 2013). The studies varied in terms of the information provided about the number of potential participants approached, the number who began or completed the intervention, and the numbers who declined or dropped out. However in a number of the studies, due to participant recruitment methods (e.g. parent support organisations), the number of participants approached was difficult to ascertain (Benn et al. 2012; Ferraiolo & Harris 2013; Singh et al. 2014; Singh et al. 2007; Singh et al. 2006). All of the five randomised control studies recruited participants through parental support

or local service authority groups, which although these were all based in North America indicated a representative sample of ethnic, educational, and economic backgrounds. Therefore, these studies may be generalisable to a population of predominately Caucasian American individuals who already access some local services.

All of the five randomised-control studies provided diagnostic information on the nature of the child's diagnosis or syndrome, however very few studies provided further information about the functioning level of the child or elaborated on how this affected the child and family's everyday functioning. All of these five studies included children who had a diagnosis within the Autism Spectrum, however these studies failed to highlight any additional intellectual disabilities or whether these children functioned within the average range, as this would predict very different levels of complex needs, behaviour difficulties, and parenting experiences (Benn *et al.* 2012; Ferraioli & Harris 2013). All of the randomised-group and the pre-post studies relied solely on parent-report questionnaires; furthermore, just one of these studies (Neece 2014) gathered information on the child's behaviour and the impact upon the family, which has been shown to predict levels of parenting distress (Baker *et al*. 2002; Neece *et al.* 2012).

There were four small-n studies, which all used a repeated-measures multiple-baseline design (Epstein 2009; Singh *et al*. 2006; Singh *et al*. 2007; Singh *et al*. 2014). These studies sample size ranged from three participants (Singh *et al*. 2006; Singh *et al*. 2014) to eight participants (Epstein 2009). Only one of these provided information on number of participants approached and those who took part (Epstein 2009). The further three small-n studies appeared to incorporate self-selected participants and no information of dropout rates were reported (Singh *et al*. 2014; Singh *et al*. 2007; Singh *et al*. 2006). Furthermore, these three studies used participants who were currently involved in the service or had requested MT input. Due to these studies recruiting self-selected parents, this skews the sample within the study and therefore may not be the representative of this population group. However, it must be noted that generalisability is often not the primary function of a small-n study. All of these four studies provided information on the diagnosis of the children in the study, and two studies (Singh *et al*. 2007; Singh *et al*. 2006) provided further detail of the children's functioning through using the Vineland Adaptive Behaviour Scales (Sparrow *et al.* 2005) to highlight the functioning age versus chronological age. This information serves to contextualise any condition or impairment specific-factors that may account for parental or family outcomes and specific stressors. These studies used a mix of self-report questionnaires and further measures, such as the use of cortisol levels measurements (Epstein 2009) and behavioural event recording by both parents and researchers relating to child problem and positive behaviour throughout the course of the studies (Singh *et al*. 2014; Singh *et al*. 2007; Singh *et al*. 2006), which provides a further objective measure of the impact of the intervention.

### *3.8 Quality and fidelity of intervention*

The interventions undertaken within the reviewed studies were generally well outlined and appeared to draw on and be rooted in manualised and well-researched interventions such as mindfulness-based stress-reduction (e.g. Kabat-Zinn 2003), the mindfulness skills within dialectical behaviour therapy (Linehan 1993) skills training, and an adapted mindfulness-based cognitive therapy for depression (Segal *et al*. 2002). Five studies employed methods to ensure fidelity to the intervention approach across groups and individual participants (Bazzano *et al*. 2013; Benn *et al.* 2012; Dykens *et al*. 20014; Neece 2014; Singh *et al*. 2014). The level of intervention ranged from nine hours (Dykens *et al*. 2014) of direct group contact to 36 hours (Benn *et al*. 2012) for the group-based interventions spread over eight or nine weeks, and from eight (Epstein 2009) to 24 hours of individual contact (Singh *et al.* 2006; Singh *et al*. 2007) over eight to twelve weeks. However, importantly three of the small-n studies allowed for a 48 to 52 week practice stage post-intervention (Singh *et al.* 2006; Singh *et al*. 2007; Singh *et al*. 2014) (*see* Table 1.2).

### *3.10 Statistical Analysis and Effect Sizes*

A range of statistical analyses were employed in the reviewed studies. Seven of the studies used theoretically informed statistics which were appropriate to analyse their research question (Bazzano *et al*. 2013; Benn *et al.* 2012; Dykens *et al*. 2014; Ferraiolo & Harris 2013; Neece 2014; Singh *et al*. 2014; Singh *et al.* 2007). One of the small-n studies relied solely on the mean scores over time (Singh *et al.* 2006). Epstein (2009) used z-score comparisons for each participant over time in the small-n study design.

As the studies reviewed used a range of statistical measures, effect sizes were calculated to provide a standardised assessment of the effectiveness of mindfulness across the areas (*see* tables 1.4 and 1.5). The majority of studies showed a large effect of MT on parent-reported stress. Studies with an active control group indicated a larger effect for the mindfulness intervention than the control group across parent depression and anxiety (Dykens *et al.* 2014) and stress (Ferraiolo & Harris 2013). Similarly, studies with non-active or waitlist control groups indicated a larger effect for the active mindfulness groups for parent stress, depression, and anxiety (Benn *et al.* 2012) and a large effect size between groups post-intervention (Benn *et al.* 2012; Neece 2014). However, there appeared to a decreased effect on parent ratings of wellbeing post intervention or between groups (Benn *et al.* 2012; Neece 2014). Within both waiting list control and treatment groups, there was little further improvement noted after a two month follow up, although between groups effect size increased in parent stress, anxiety, and wellbeing, the between group effects decreased for parent depression after follow up (Benn *et al.*, 2012). Other studies indicated that intervention effects were maintained for parent stress after a follow up period of up to three months (Bazzano *et al*. 2013, Ferraiolo &

**Table 1.4 Within group effect sizes across studies (Cohen's *d*)**

| | | Parent stress | Parent depression | Parent anxiety | Parent wellbeing | Child aggressive behaviour |
|---|---|---|---|---|---|---|
| Dykens et al. (2014) | MT | | | | | |
| | Post-MT | - | 1.03 | 0.88 | - | - |
| | Follow-up | - | - | - | -0.43 | - |
| | Active control | - | - | - | - | - |
| | Post-Tx | | 0.58 | 0.44 | - | - |
| Singh et al. (2007) | MT | | | | | |
| | Post-MT | 4.61 | - | - | - | 2.07 |
| | Follow-up | - | - | - | - | 7.65 |
| | No Cx group | - | - | - | - | - |
| Singh et al. (2014) | MT | | | | | |
| | Post-MT | 0.62 | - | - | - | 1.64 |
| | Follow-up | 3.98 | - | - | - | 4.44 |
| | No Cx group | - | - | - | - | - |
| Singh et al. (2006) | MT | | | | | |
| | Post-MT | - | - | - | - | 0.21 |
| | Follow-up | - | - | - | - | 2.47 |
| | No Cx group | - | - | - | - | |
| Bazzano et al (2013) | MT | | | | | |
| | Post-MT | 1.0 | - | - | -0.65 | - |
| | Follow-up | 1.88 | - | - | -1.34 | - |
| | No Cx group | - | - | - | - | - |
| Benn et al. (2012) | MT | | | | | |
| | Post-MT | 0.71 | 0.38 | 0.72 | -0.08 | - |
| | Follow-up | -0.14 | -0.09 | -0.22 | -0.27 | - |
| | WL control | | | | | |
| | Post-Tx | 0.34 | -0.05 | 0.16 | 0.02 | - |
| | Follow-up | -0.31 | 0.12 | -0.15 | -0.1 | - |
| Ferraioli & Harris (2013) | MT | | | | | |
| | Post-MT | 2.03 | - | - | - | - |
| | Follow-up | 1.01 | - | - | - | - |
| | Active control | | | | | |
| | Post-Tx | 0.03 | - | - | - | - |
| | Follow-up | 0.27 | - | - | - | - |
| Epstein (2009) | MT | | | | | |
| | Post-MT | 0.83 | - | - | - | - |
| | Follow-up | 0.62 | - | - | - | - |
| | No Cx group | - | - | - | - | - |
| Neece (2014) | MT | - | - | - | - | - |
| | WL Control | - | - | - | - | - |

Harris 2013). The small-n design studies indicated significantly stronger effects of MT for individual parents after a 48 to 52-week mindfulness practice period (Singh *et al.* 2006; Singh *et al.* 2007; Singh *et al.* 2014).

Overall, these effects sizes indicated that MT was effective in decreasing child behaviour problems (Singh et al. 2006; Singh et al. 2007; Singh et al. 2014) parental stress, anxiety, and depression and in comparison to other parent group training or waiting list controls (Bazzano et al. 2013; Benn et al. 2012; Dykens et al. 2014; Ferraiolo & Harris 2013; Neece 2014) an individual's in small-n

studies (Singh et al. 2014; Singh et al. 2007). Between group effect sizes indicated a significant difference between MT groups and controls post-training and in follow-up (Benn et al. 2012; Ferraioli & Harris 2013; Neece 2014).

**Table 1.5 Between group effect sizes across studies (Cohen's *d*)**

| | | Parent stress | Parent depression | Parent anxiety | Parent wellbeing | Child aggressive behaviour |
|---|---|---|---|---|---|---|
| Dykens et al. (2014) | MT / PAD control | | | | | |
| | Post-MT | - | - | - | - | - |
| Singh et al. (2007) | No control group | - | - | - | - | - |
| Singh et al. (2014) | No control group | - | - | - | - | - |
| Singh et al. (2006) | No Control group | - | - | - | - | - |
| Bazzano et al. (2013) | No control group | - | - | - | - | - |
| Benn et al. (2012) | MT / WL control | | | | | |
| | Post-MT | -0.40 | -0.51 | -0.52 | 0.13 | - |
| | Follow-up | -0.79 | -0.27 | -0.75 | 0.40 | - |
| Ferraioli & Harris (2013) | MT / Skills group | | | | | |
| | Post-MT | 1.59 | - | - | - | - |
| | Follow-up | 0.63 | - | - | - | - |
| Epstein (2009) | No Control group | - | - | - | - | - |
| Neece (2014) | MT / WL Control | | | | | |
| | Pre-MT | 0.29 | 0.03 | - | 0.20 | 0.04 |
| | Post-MT | 0.70 | 0.87 | - | 0.90 | 0.33 |

### *3.9 Generalisability & Quality of Reporting*

The generalisability of the papers ranged from poor to adequate, with the majority of the studies rated as adequate (Bazzano *et al*. 2013; Dykens *et al*. 2014; Epstein 2009; Ferraioli & Harris 2013; Neece 2014). Benn *et al*. (2012) did not provide enough information to ascertain the generalisability of their results to similar groups. Three small-n studies reviewed were not considered to be generalisable due to the study design and lack of variance in participant characteristics (Singh *et al.* 2006; Singh *et al*. 2007; Singh *et al*. 2014). The main factors underlying generalisability were the underrepresentation, the specific populations studied, the self-selecting participants used in some of the studies and the tendency for samples to be recruited via parent support organisations. The findings in these studies should therefore be generalised with caution as they may not represent a varied sample of parents. The quality of reporting across all of the nine studies was judged to be adequate or good.

## 4. Synthesis of Results

### *4.1 Parent Outcomes*

The primary parental psychological outcomes were stress, anxiety, depression, and levels of mindfulness. Eight of the studies showed a significant decrease in stress and anxiety experienced by parents after a MT (Bazzano *et al*. 2013; Benn et al. 2012; Dykens et al. 2014; Ferraiolo & Harris 2013; Neece 2014; Singh *et al*. 2014; Singh *et al*. 2007; Singh *et al*. 2006). Similarly, depression or mood disturbance scores decreased (Neece 2014; Dykens *et al*. 2014) and positive functioning increased (Benn *et al*. 2012; Bazzano *et al*. 2013; Dykens *et al*. 2014) for parents post-intervention. The studies which used a control group indicated significantly greater improvements for MT group participants on all psychological outcomes compared to controls in both waitlist-control groups (Neece 2014; Benn et al. 2012) and active control groups (Ferraiolo & Harris 2013; Dykens et al. 2014). However, one small-n design study indicated a non-significant decrease of self-reported stress post-intervention, although an increase in self-efficacy and a significant decrease in cortisol levels were noted (Epstein 2009). Eight of the nine studies reviewed reported significant improvements in outcomes after MT, including the papers rated as methodologically strong (Bazzano *et al*. 2013; Benn *et al*. 2012; Dykens *et al*. 2014; Neece 2014). These four most highly rated studies reported significantly decreased stress (Bazzano *et al.* 2013; Benn *et al*. 2012; Dykens *et al*. 2014; Neece 2014), depression (Dykens *et al*. 2014; Neece 2014), and anxiety (Benn *et al.* 2012; Dykens *et al*. 2014) in parents post-intervention. Furthermore, they reported a number of positive outcomes, such as; improved life satisfaction (Dykens *et al*. 2014; Neece 2014), wellbeing (Bazzano *et al*. 2013; Dykens *et al*. 2014), and increased mindfulness and self-compassion (Bazzano *et al*. 2013; Benn *et al.* 2012).

Effect sizes indicated that MT was effective for decreasing parental stress and anxiety. However, MT appeared to have a less clear and weaker effect on parental depression, effect sizes ranged from $d = 1.03$ to $d = 0.38$ for post-MT (Benn *et al.* 2012; Dykens *et al*. 2014). Further, the maintenance of this change over time; studies indicated a mixed picture of further positive change between post-MT and follow-up times (Ferraiolo & Harris 2013) and a decrease in effect of MT at follow-up (Benn *et al*. 2012). This highlights potential difficulties in the maintenance of positive change over time, particularly after shorter periods of intervention (Hansen *et al*. 2002). Further, studies which used up to 52 weeks monitored practice periods post-MT indicated larger effects of MT on parental stress post follow-up (Singh *et al.* 2014); further indicating the importance difference in treatment dosage across these studies and the impact this may have on outcomes. Despite the known impact of normalising, group cohesion, and added social support within group interventions (Cruwys *et al*. 2015; Yalom & Leszcz, 2005), the individual interventions illustrated larger effects. These studies provided an outline of the weekly mindfulness programme, however no measure of treatment

fidelity across individual participants was provided to evaluate the therapist's adherence to the protocol.

### *4.2 Child Outcomes*

Four of the nine studies measured child behavioural outcomes through observational questionnaires and event-recording procedures (Neece 2014; Singh *et al*. 2014; Singh *et al*. 2007; Singh *et al*. 2006). These indicated that the children of the parents who received a mindfulness intervention displayed significantly less attentional and hyperactive behaviours and symptoms than the waitlist-controls post intervention (Neece 2014). Similarly, three of the small-n studies indicated a reduction in challenging behaviour (aggression, self-injurious, and non-compliance) displayed by the children of participants post-intervention (Singh *et al*. 2014; Singh *et al*. 2007; Singh *et al.* 2006).

Studies which measured child outcomes indicated a strong effect of MT on the reduction of child behaviour, in particular child aggression (Singh *et al.* 2014; Singh *et al*. 2007; Singh *et al*., 2006). This effect was particularly strong after an extended monitored practice stage of 48 to 52 weeks. Similarly, the between groups effect size indicated a change between groups MT and waiting list control after the intervention in child outcomes (Neece 2014). These results indicate the impact of lengthened practice stage or treatment dosage (Orlinsky *et al.* 1994; Steenbarger 1994; Hansen *et al*. 2002), in particular impact of formal support and monitoring may have a large impact on individual outcomes. Despite these large effect sizes, extrapolating or generalising the effect of mindfulness from these findings must be cautioned, due to the self-selected nature of the participants, the lack of clarity of treatment fidelity regarding the specific components of mindfulness and measure across individual interventions.

## 5. Discussion

The key findings highlighted significant improvements in self-report parental psychological outcomes (mental health, wellbeing, mindfulness and self-compassion) after an individual or group-based MT in eight out of the nine studies. That is, that a group or individual MT was more effective in decreasing negative parent psychological outcomes and increasing positive psychological outcomes (self-efficacy, mindfulness, well-being, satisfaction with life, and satisfaction with parenting) than non-active control groups (Benn *et al*. 2012; Neece 2014), a skills-based group (Ferraiolo & Harris 2013), a positive adult development group (Dykens *et al.* 2014), and within-individual post-intervention (Bazzano *et al*. 2013; Singh *et al*. 2014; Singh *et al*. 2007; Singh *et al*. 2006). However, the quality and methods of the reviewed studies varied; such as the specific components of mindfulness used within the interventions differed, two studies did not provide an outline of the specific mindfulness components used (Dykens *et al* 2014; Neece 2014), and only

five studies employed methods to control and measure the fidelity of the intervention (Bazzano *et al*. 2013; Benn *et al.* 2012; Dykens *et al*. 20014; Neece 2014; Singh *et al*. 2014).

Furthermore, the difference between studies format of individual and group treatment formats (Cruwys *et al*. 2015) and dosage or amount of treatment provided (Hansen *et al*. 2002) may impact the effect of the intervention. Many of the studies looked differing outcomes; e.g. parent stress, anxiety, and depression, making direct comparison of outcomes difficult. However, overall it appears that studies which used individual mindfulness interventions and a longer period of intervention or practice period of mindfulness skills showed a larger effect size. The generalisability of these findings are interpreted in light of small self-selecting samples and differences in the content and method of intervention.

### *5.1 Clinical Implications*

Clinicians need to be aware of the impact of caring for a child with a disability, in terms of parental wellbeing and coping and the effect that this may have on child behaviour and outcomes. The bidirectional nature of the relationship between parental stress and child behaviour has been highlighted both within the current review and in previous literature (Bailey *et al*. 2007; Singer 2007). Previous research has indicated that a mixed approach of skills training and behaviour management training is most useful within this population (Singer 2007). This idea revolves around the bidirectional relationship between parental stress levels and child behaviours, and that when parents manage behaviours as learnt through behavioural training this positively impacts the child behaviour and therefore the parents level of distress. However, it may be that some behavioural approaches are very difficult to implement, are unsuccessful, or the problem behaviour is linked to the child's diagnosis or developmental stage and therefore is not easily addressed. These situations may be particularly difficult for parents and therefore the persistent stress may impact the parents' mental health and well-being. This review highlights the mindfulness-based approaches may be useful in helping parents to cope with behaviours without explicitly addressing them and that mindfulness approaches appear to indirectly influence the frequency of child problem behaviours, as measured through parent and objective frequency rating and event recording in-vivo and through video recording (Singh *et al.* 2006; Singh *et al*. 2014). Parental stress and coping are not often directly targeted in interventions within this population; however this review highlights the clinically useful nature of focusing on parental wellbeing and the effectiveness of using a mindfulness-based approach in addressing these areas.

The current review highlights the promising outcomes in this area and the usefulness of these MTs to be used in conjunction with commonly used interventions in this area, such as behavioural interventions, skills training, and psychoeducation.

### *5.2 Implications for Research*

This review has highlighted some recent research in a growing area: the effectiveness of mindfulness interventions as approaches targeted to parents of children with disabilities and the increased stressors and pressures experienced by this population. The current review outlined some of the recent advancements in considering the necessity of effectiveness of a targeted intervention for parents of children with intellectual disability and developmental disability and their mental health or well-being. However, this is clearly an area that requires further research and development. From the current review it is unclear whether mindfulness interventions are more efficacious than other interventions, such as commonly used parenting groups, or individual interventions such as cognitive behaviour therapy or parent support groups. Furthermore, greater diversity in samples and greater representation of fathers would allow greater clarity as to the generalisability of these findings and implications for different populations.

### *5.3 Strengths and Limitations of the Review*

This is the first systematic exploration of MTs and psychological outcomes for parents of children with intellectual or developmental disabilities, due to specific diagnosis or unknown aetiology. It offered possible implications for future practice and useful interventions for professionals working with this group of families. However, the review has a number of limitations that mean the results and conclusions may not be readily generalisable beyond the populations studied. All of the studies reviewed were based in North America and with a sometimes limited and unrepresentative group of parents. Approaches to mindfulness and its application may differ in different cultures, even across English speaking countries. Furthermore, many of the samples included in the papers were predominantly Caucasian, middle-class parents. Therefore, it would be important to examine the impact of these interventions within different countries and broader groups of parents. The fidelity to treatment outline was not measured in a number of the studies, and each of the studies measured slightly different parental outcomes; this makes direct comparison between studies difficult. Further, none of the reviewed studies acknowledged the additional effect of the intervention type format; that is individual intervention compared with group intervention (Cruwys *et al*. 2015).

Finally, some types of studies were excluded from the review in order to maintain consistency of methodological appraisal, in particular, studies that used interventions such as Acceptance and Commitment Therapy (ACT), due to additional cognitive, emotional, and behavioural aspects which encompass the therapy. However, it would be useful to compare the effectiveness of ACT, particular MTs, and mindfulness in conjunction another intervention.

## 6. Conclusions

Research investigating the impact and usefulness of MTs on parental psychological outcomes for parents of children with an intellectual or developmental disabilities is steadily growing. A number of good quality randomised-group and small-n design studies have been conducted over the previous six years that provide evidentiary support for the utility of MTs. The majority of studies reviewed indicated that parental distress decreased and well-being increased after a MT. There is now a need to build upon these findings and to further explore the effectiveness and impact of particular mindfulness interventions on parental distress, well-being, and child behaviour. Good quality research in this area will enable the development of an evidence base that will inform future service interventions and treatment guidelines to enhance the psychological well-being of those caring for a child with a disability and therefore promote the well-being of the child and wider family.

## 7. Declaration of interests

The primary author conducted the systematic review as port of a portfolio thesis for a Doctorate in Clinical Psychology undertaken at the University of Edinburgh. This training place was jointly funded by NHS Education Scotland and NHS Lothian Health board. No other funding or support was received.

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## Chapter 2: Journal Article

# The Role of Parental Locus of Control and Child Behaviour on Subjective Wellbeing for Mothers of Children with Heterogeneous Intellectual and Developmental Disabilities


## Abstract

*Background:* Parenting a child with an intellectual or developmental disability is associated with higher levels of stress and depression. However, there appears to be some variance between parents in their level of coping.

*Aims:* This study aims to explore the impact of maternal variables (parental locus of control), child variables (child positive and problem behaviour), and demographic variables on subjective wellbeing.

*Method:* A cross-sectional sample of mothers (N = 114) completed self-report measures of Parental Locus of Control, Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS), and the Nisonger Child Behaviour Rating Form.

*Results:* Mediation analysis indicated parental locus of control, in particular the three sub-domains of child control, and parent efficacy significantly mediated the relationship between child problem behaviour and parental wellbeing.

*Conclusions:* These results highlight the importance of particular parental attributions in influencing the wellbeing of parents of children with intellectual and developmental disabilities. Further, it highlights significant differences between diagnostic groups and demographic factors. These findings may inform future practice with these families.



**Keywords: i**ntellectual, developmental, disability, parental locus of control, wellbeing, behaviour

## 1. Introduction

The experience of parenting a child can often be stressful, however research indicates that mothers of children with a developmental disability (DD) or intellectual disability (ID) often face challenges that are not shared by parents of typically developing children (Abbeduto *et al.*, 2004; Lee, 2013; Stoneman, 1996). Stress refers to an environmental, social, or internal demand which requires an individual to change their usual pattern or behaviour (Holmes & Rahe, 1967). Mothers often report not just increased stress, but a more emotionally demanding daily life than other parents (Baker, Blacher, & Olsson, 2005; Neece & Baker, 2008). For example, coming to terms with the child's diagnosis or condition, providing specialised care, planning for future care-taking, and practical daily demands and stressors are some of the common demands experienced by parents of children with disabilities (Lee, 2013).

A stress reaction is considered to be the physiological and emotional arousal evoked by the perceived level of stress and coping is the emotional and behavioural strategies used to deal with the stressor and the physical or emotional reactions to the stressor (Lazarus & Folkman, 1984). Individuals use personal coping resources; the social and personal characteristics, to allow the person to cope with a stressor. The cumulative effect of increased daily life stressors, rather than individual disability itself, has been associated with parental psychosocial functioning (Wallander & Varni, 1998). Previous research has indicated that increased parenting stress, anxiety, depression, and lower levels of wellbeing are experienced by both mothers and fathers of children with ID and DD (Dyson, 1997; Foster *et al.*, 2010; Roach *et al*., 1999; Singer, 2006). Wellbeing is considered to be not just the absence of mental ill health, but also the presence of an individual's psychological, social and physical resources which is needed to meet psychological, social and physical challenges. When there is a cumulative effect of challenges or stressors and individuals have more challenges than resources, their level of wellbeing decreases (Dodge, Daly, Huyton, & Sanders, 2012). Anxiety and depression are positive indicators of mental ill health and distress, which may be associated with increased long-term demands, stressors, and decreased wellbeing (Abbeduto *et al.*, 2004; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Dyson, 1997). Anxiety is associated with the experience of fear, worry, and apprehension, often in response to a particular thought or stimulus, while depression is associated with feelings of sadness, sorrow and hopelessness (Bjelland, Dahl, Haug, & Neckelmann, 2002).

After their child receives a diagnosis of both a medical condition and developmental disability or syndrome parents tend to experience a common pattern of grief and adaption; as shock and denial, sadness, despair, emotional disorganisation and guilt, and lastly emotional adaptation and acceptance (Fortier & Wanlass, 1984; Blacher, 1984). Feniger-Schaal and Oppenheim (2013)

showed that mothers who had not reached the final stage of coping over time, involving parental reorganisation and adjustment to the new view of the child, displayed less sensitivity and understanding to their child's behaviour. This decreased understanding as to child presentation and behaviours may relate to perceived parental control and impact parental wellbeing (Hagekull, Bohlin & Hammarberg, 2001; Hassall, Rose, & McDonald, 2005; Jones & Passey, 2005; Lloyd & Hastings, 2009b). Following diagnosis and the period of waiting for an intervention can be one of the most stressful periods for parents, as they attempt to adjust through the initial stages of grief and adaption (Aarons & Gittens, 1992; MacDermott, Williams, Ridley, Glasson, & Wray, 2006). Over time parents may learn to adapt, manage their quality of life, and wellbeing more effectively (Osborne *et al*., 2012) and within family conflict reduces (Petalas *et al*., 2012). Therefore time since diagnosis can play an important role in parents coping, level of stress, and overall feeling of wellbeing.

The literature illustrates a mixed picture in relation coping in mothers of children with disabilities with varying aetiologies; relating to a specific syndrome (e.g. Fragile X syndrome, Cornelia de Lange, or Angelman syndrome), chromosomal deletions or disorders, and developmental (e.g. autism) or intellectual disability due to an unknown aetiology, with some suggestion of differing caregiver across diagnostic groups. Parents of children with Down syndrome often report lower levels of stress (Hauser-Cram *et al*., 2001; Kasari & Sigman, 1997) and less pessimism (Fidler, Hodapp, Dykens, 2000) than mothers from a more heterogeneous group (Abbeduto *et al.*, 2004). Mothers of children with rarer genetic syndromes (e.g. Cri du Chat, Angelman, Cornelia de Lange) and mothers of children with co-morbid Autism Spectrum Disorder (ASD) and an ID are at a higher level of risk for stress, mental health problems, and lower wellbeing than parents of children with a heterogeneous aetiology (Abbeduto *et al*. 2004; Blacher & McIntyre 2006; Duarte *et al.* 2005; Estes *et al.*, 2009; Griffith *et al*., 2011; Lewis *et al.*, 2006). However, there is nothing inherent in a particular diagnosis that would intrinsically evoke a particular set of parental reactions or stress response (Abbeduto *et al*., 2004), and it is likely that there are further variables affecting these group differences. For example, differences in parental coping according to child diagnosis were minimised when groups were matched on child characteristics (Cahill & Glidden, 1996) or the family's need for recent service input (Schieve *et al*., 2007), in particular child behaviour problems are a strong predictor of parental stress (Wulffaert *et al.* 2009).

Child factors that have been explored extensively include adaptive and maladaptive behaviours, social/communication skills, cognitive level, and sensory difficulties (e.g., Baker *et al*., 2002, 2003; Kirby, White, & Baranek, 2015; Davis & Carter, 2008; Neece & Baker, 2008; Weiss, Sullivan, &

Diamond, 2003). However, these challenges tend to vary greatly across diagnoses and individuals, and therefore we need to look beyond the contributions of child and diagnostic characteristics to explain this variance. A broad range of variables have been investigated to explain variation in parental psychological wellbeing and research indicates that this variance remains in families with similar levels of difficulties relating to income, social support, and severity of disability (Abbeduto *et al.*, 2004; Goodley & Tregaskis, 2006; Stoneman, 1996). Therefore, the differences in parental stress, mental health and wellbeing are likely to have several origins, both outwith the parent (e.g. child characteristics, financial strain, relationship strain) and in relation to the parent (e.g. genetics, parental characteristics, parental beliefs and cognitions). A range of cognitive factors have been studied in relation to the stress-coping process, including self-efficacy (Hastings & Brown, 2002; Kuhn & Carter, 2006), hope (Lloyd & Hastings, 2009a), parental acceptance (Lloyd & Hastings, 2008), and Locus of Control (Lloyd & Hastings, 2009b).

The concept of Locus of control (LOC) represents an individual's perception or belief of their control over their environment and this may affect the individual's response to situations (Lefcourt, 1982), and has developed since the original concept as outlined by Rotter (1966). These beliefs range from weak or no personal control (external locus of control) to strong personal control (internal locus of control). There are a number of related concepts of personal causation (deCharms, 1968) and Bandura's (1977) self-efficacy; that is; an individual's judgement of how well they can perform across a variety of situations (Smith, 1989). LOC has been shown to share some common attributes with generalised self-efficacy; Judge and colleagues (2002) carried out a large exploration into the relationship between measures of self-esteem, neuroticism, LOC, and generalised self-efficacy. Their meta-analytic results indicated that measures of LOC were moderately related to generalised self-efficacy. Further investigation of LOC, as measured by the IPC scale (Levenson, 1981), and personality traits (NEO-FFI; Costa & MacCrae, 1992), indicated across four combined and weighted studies that LOC was related to conscientiousness (r = .31), extraversion (r = .26), openness (r = .24), and agreeableness (r = .19) (Judge *et al*., 2002). However, LOC is thought to be situation-specific or an interactionist concept (Reid, 1977); and can vary depending on the situation and behaviour. That is; a parent may vary their beliefs of control in their parenting in relation to different aspects of their parenting experience.

Studies which used more general locus of control measures with parents of children with intellectual disabilities tend to show low personal control is associated with higher parenting stress and psychological distress (e.g. Sloper e*t al.*, 1991; Wiggs & Stores, 2001). Hassall and Rose (2005) suggest that these early findings demonstrate the value in exploring this relationship with a more specific measure of parental locus of control with this group of parents. Parental Locus of Control

(PLOC) more specifically relates to the parent experience of parenting their child, in particular the context of how their child's perceived behaviour and development is determined by them as parents (internal) or other factors (external) within the parent-child relationship (Campis, Lyman, & Prentice-Dunn, 1986; Lloyd & Hastings, 2009b). Parental locus of control (PLOC) has been associated with parental stress (Lloyd & Hastings, 2009b), pessimism (Rimmerman, 1991), depression (Dunn, Burbine, Bowers, &Tantleff-Dunn, 2001), anxiety (Lloyd & Hastings, 2009b), and family adaptation (Henderson & Vanderberg, 1992). In a longitudinal study to explore the influences of parental experiences on child development, Hageskull and colleagues (2001) used two sub-scales of the PLOC ('parental responsibility' and 'parental control') to measure parental perceived control. The sub-scale of 'parental control' was predictive of less perceived control in both mothers and fathers, and this was associated with greater aggressiveness and internalizing problems in the children (Hagekull, Bohlin and Hammarberg, 2001). Further research supported this view that those who report a more external locus of control report higher levels of behavioural difficulties (Lloyd & Hastings, 2009b), feel less control in relation to their child's behaviours (Hassall, Rose, & McDonald, 2005), and that their child's need dominated their life (Jones & Passey, 2005). Hamlyn-Wright, Lorenz, and Ellis (2007) indicated more external PLOC in parents of children with autism compared to Down syndrome and typically developing children, and total LOC mediated the relationship between parental stress and both depression and anxiety. This reflects previous findings within wellbeing across diagnoses. Similarly, perceived low parenting control is associated with higher parenting stress in mothers of children with intellectual disabilities (Hassall *et al*., 2005). Building on these findings, it would be of interest to further investigate the relationship between PLOC, child behaviour and wellbeing.

### *1.1 Aims and hypotheses*

The current study aimed to explore the relationship between subjective wellbeing of parents in relation to both child (child diagnosis, behaviour, and level of ID) and parent characteristics (total PLOC, its sub-domains) and across levels of intellectual disability or diagnosis.

It was hypothesised that:

1. Parental Locus of Control sub-domains of child control, parent control, parent responsibility, and parent efficacy will be significantly negatively correlated with parental wellbeing.
2. Total Parental Locus of Control Revised will mediate the relationship between child problem behaviour and maternal wellbeing.
3. The relationship between child problem behaviour and maternal wellbeing will be significantly mediated by the Parental Locus of Control sub-domains of child control, parent control, and parental efficacy.

## 2. Method

### *2.1 Participants*

A total of 432 participants accessed the online questionnaire pack, 131 participants completed the study, giving a response rate of 30.3 percent. Due to the low rate of male respondents (6%), it was decided that the study would be more effective in focusing on the maternal population. A further nine non-native English speaking participants (6%) were removed, due to potential impact of language on completing measures. Another individual participant was excluded as they had left an entire scale incomplete. It was decided to be more robust to exclude this dataset rather than to employ pairwise deletion or impute data for entire scales. Therefore the final sample of 114 mothers took part in this cross-sectional, self-report questionnaire based study. Age ranged from 25 to 59 years, with a mean of 43 years. Full demographic information is shown in Table 2.1. Participants were included in the study if they cared for a child of 18 years or younger with a diagnosis of a syndrome, chromosomal disorder, or developmental disability which led to intellectual disability, impaired learning, and an increased caring needs. Given the self-selecting nature of participation, those who took part were those who viewed themselves as a parent or carer. Further participant and child information is provided in Tables 2.1 and 2.2, respectively.

### *2.2 Procedure*

Recruitment was undertaken through two primary routes: through the specialist education provision for children and young people with intellectual disabilities and through voluntary organisations and charities for children with intellectual disabilities. Voluntary organisations were contacted and advertisements for the survey and a link to the online survey were published on organisations' websites, emailed in organisations' newsletters, and posted on their social media. Families attending child ID specialist services and local special school provisions were posted an invitation and advertisement to take part in the survey with a link to the online survey (*see* Appendix 6 and 8). Participants completed the study online via a secure survey website, this allowed mothers to participate during a time that suited them and the questionnaires could be completed in stages. Participation was voluntary and it was made clear that whether individuals participated or not would not affect any services that the families currently received. Completion and submission of the questionnaires was deemed as giving informed consent for responses to be used for the purpose of the study and participants were made aware of this.

**Table 2.1: Participant demographic information**

| | | % of sample, n =114 |
|---|---|---|
| **Age in years** | 25 - 34 | 8.9 |
| | 35 - 44 | 51.2 |
| | 45 - 54 | 31.4 |
| | 55 - 59 | 8.4 |
| **Employment** | Full-time | 15 |
| | Part-time | 30.1 |
| | Not Employed | 40.7 |
| | Other | 14.2 |
| **Marital Status** | Single | 7.9 |
| | Married/Partner | 85.9 |
| | Divorced/Separated | 6.1 |
| **Country** | United Kingdom | 78.5 |
| | Ireland | 21.4 |
| **Total num. of children** | One child | 16.7 |
| | Two children | 45.5 |
| | Three children | 25.4 |
| | Four children | 7.9 |
| | Five children | 3.5 |

**Table 2.2: Child sample demographics**

| | | % of sample, n = 114 |
|---|---|---|
| **Gender** | Male | 69.3 |
| | Female | 30.7 |
| **Child Age** | 0 – 5 | 17.6 |
| | 6 – 11 | 40.3 |
| | 12 - 18 | 42.1 |
| **Primary Diagnosis** | ASD | 39.5 |
| | ID | 7 |
| | Down Syndrome | 22.8 |
| | Other syndrome[1] | 10.5 |
| | Birth/brain injury | 3.5 |
| | Chromosomal Disorder/Syndrome | 16.7 |
| **Secondary Diagnosis** | ASD | 23.7 |
| | Epilepsy | 7.9 |
| | Cerebral Palsy | 1 |
| | Medical Complications | 7 |
| | Visual Cortical Blindness | 5.3 |
| | None | 55.1 |
| **Level of Intellectual Disability** | Mild | 20.2 |
| | Moderate | 38.6 |
| | Severe | 31.6 |
| | Unsure | 9.6 |
| **Medication** | Yes | 58.3 |
| | No | 41.7 |

[1]Cri du Chat syndrome, Fragile X syndrome, Hirschsprungs, Rubinstein-Taybi syndrome, CHARGE syndrome, Smith Lemil Opitz syndrome, Rett syndrome, Angelmans syndrome, Joubert syndrome, tuberous sclerosis

*2.3 Measures*

Participants were first asked to provide demographic information about themselves and the child they cared for, before completing a battery of self-report questionnaires.

*The Parental Locus of Control Scale – revised version* (PLOC-R) was used to measure parents' locus of control within the parent-child relationship. This was adapted from the original version (Campis, Lyman, & Prentice-Dunn, 1986), to be used specifically for parents of children with ID (Lloyd & Hastings, 2009b) and further adapted to a five-point scale in a recent study with the addition of neutral midpoint (Coffait, 2012), and this was replicated in this study. Lloyd and Hastings (2009) used an item-reduction procedure to develop a robust revised version of the measure with acceptable alpha levels across all sub-scales; 8 items for parental efficacy (.69), 9 items for parental responsibility (.81), 5 items for child control (.70), 9 items for fate/chance (.67), and 10 items for parent control (.82). Coffait (2012) indicated good internal consistency of the PLOC-R with an added 'not sure' neutral point on the Likert scale (Chronbach $\alpha = .92$). However, no further confirmatory factor analyses were carried out after the addition of the neutral midpoint.

The current study indicated a Cronbach's alpha score of .81. The scale contains 42 statements, including nine reverse-score items, which are summed to map onto five subscales. Within the current study each of these scales demonstrated good reliability; parental efficacy (.79), parental responsibility (.77), belief in fate or chance (.73), child control (.83), and parent control (.72). The maximum score on the PLOC-R is 210, with higher scores indicating a more external locus of control in relation to the parent child relationship.

*The Warwick-Edinburgh Mental Wellbeing Scale* (WEMWBS; Stewart-Brown *et al.*, 2009) was used to measure parent and carers' subjective psychological wellbeing. This scale is useful due to its brevity and its focus on positive mental health and psychological wellbeing, rather than the presence or absence of a mental health problem. The 14 items cover positive thoughts and feelings using a five-item Likert scale, which ranged from 'none of the time' to 'all of the time', the maximum score of 70 indicates good overall wellbeing. There is no measure of subjective wellbeing that has been developed specifically for parents of children with a Learning Disability, thus the WEMWBS appears suitable due to its general nature and its previous use with parents in an evaluation of parenting interventions (Lindsay *et al*., 2008), and in relation to locus of control in parents of child with profound and multiple disabilities (Coiffait, 2012). This scale has been validated in previous research for adults aged 16 and above, it was standardised using student and general population samples, and more recent research explored its validity using focus groups (*see* Stewart-Brown *et al*., 2009; Tennant *et al.,* 2007). The WEMWBS has been indicated to be

psychometrically robust; the current sample indicates a Cronbach's alpha of 0.95. Previously it has been illustrated to show strong construct validity, test-retest reliability, and content validity (Tennant *et al*., 2007).

*The Nisonger Child Behaviour Rating - Parent Form* (Nisonger CBRF; Aman *et al.,* 1996) is a widely used parental-report questionnaire of subjective behaviour. The NCBRF – parent version contains two sections: social competence and problem behaviours. The social competence section contains 10 items which focus on adaptive and pro-social behaviours, which are rated on a 4-point Likert scale ranging from 0 (not true/none) to 3 (completely or always true). These are summed and plot onto two subscales, Compliant/calm and Adaptive social (Tassé e*t al*., 1996). The problem behaviour section consists of 60 items of maladaptive behaviours to assess several broad dimensions of maladaptive behaviour common in children with ID and DD, including conduct problem, insecure/anxious, hyperactive, self-injury/stereotypic, self-isolated/ritualistic, and overly sensitive (Tassé *et al.*, 1996). Possible index scores ranged from 0 to 198, with higher scores indicated more frequent and severe behaviour problems. Raters are instructed to consider both the rate of occurrence and the degree to which the behaviour was a problem over the previous month. This measure was chosen due to the variety of behaviours covered, in particular the applicability of these to the common and more complex behaviours noted within a Intellectual Disability population.

The NCBRF is gaining popularity (*see* Rush & Frances, 2000). It has been used as an outcome measure in placebo controlled trials of children with mild developmental disabilities (Aman *et al*., 2002; Findling *et al*., 2004; Reyes *et al*., 2006; Snyder *et al*. 2002), in research studies to measure behaviour and emotion difficulties in children with Pervasive Developmental Disorders (PDD), ASD, and Smith-Lemi-Opitz Syndrome (Benson 2015; Benson, 2014; Lecavalier, 2006; Lecavalier & Wiltz, 2006; Shea *et al*., 2004; Tierney *et al*, 2001; Tse *et al*., 2007), and has been translated into several languages, showing a similar factor structure and good psychometric properties (Tassé, Girouard, & Morin, 2000; Tassé & Lecavalier, 2000). The NCBRF has been shown to be a useful measure of behaviours in the ID and ASD populations (Lecavalier *et* al., 2004; McConachie *et al*., 2015). Previous studies and factor analyses have indicated a good internal consistency of the NCBRF, with Cronbach's alpha coefficients between 0.92 and 0.71 for all subscales (Lecavalier *et al.*, 2004), test–retest reliability for the parent version was reported to be strong (ICC for total problem behaviour > 0.80) (McConachie *et al*., 2015), and good evidence for divergent and convergent validity of the NCBRF (Lecavalier *et al*., 2004). The current study indicated an overall Cronbach's alpha of 0.95.

*2.4 Data screening*

Empirical estimates of sample size required for 0.8 level of power were derived by Fritz and MacKinnon (2007). Preliminary statistics indicated the alpha path was between small and medium ($\alpha = .22$), and the beta path was medium ($\beta = .335$) and therefore as the current study used bias-corrected bootstrapping (n=5000) throughout the mediation analyses, an estimated sample of 115 participants was suggested. Further bootstrapping (n=1000) was used throughout statistical analyses to provide increased power. Data was initially screened to ensure that assumptions of further analyses were met. Histograms and boxplots were examined to ensure no outliers were present while as the assumptions of linearity and homoscedasticity were found to be met through examination of scatterplots. Pearson correlations were calculated between all predictor variables of the planned mediation analysis to test for multicollinearity. No extremely high correlations i.e. > 0.9, were identified, suggesting that all items were suitable for inclusion in further analyses (Field, 2013; Preacher & Hayes, 2008).

Missing data was examined to identify any patterns using Little's MCAR test (Little, 1988), the results indicated that there was no missing data in the PLOC-R and WEMWBS scales, data in the NCBR was missing at random. Expectation maximisation (Howell, 2007) was used to impute missing data, to avoid difficulties associated with simplistic methods. This method was used on each subscale individually to increase the accuracy of predicted values.

Pearson product moment correlations with bootstrapping were used to explore the relationship between behaviour, locus of control, and wellbeing and to explore the relationships between subscales and possible mediators. Finally, a product of coefficients mediation linked with bootstrapping analysis; n = 5000 bootstrapping samples, (Preacher & Hayes, 2008; Hayes, 2009) was used to explore possible mediating relationships. This mediation method has been chosen as it conducts all possible pairwise contrasts between indirect effects which will allow for comparison of the roles of each mediator. All 95% confidence intervals reported in this study were (Bca) bias corrected and accelerated (Field, 2013). Point estimates of indirect effects were considered significant when zero did not fall between identified confidence intervals. Statistical significance was defined as $p < 0.05$, two tailed. A lower level of *p* value (<0.0005) was adopted to control for type 1 errors arisen from multiple analyses (Field, 2013).

## 3. Results

### *3.1 Descriptives*

**Table 2.3: Descriptive data for all measures**

| | Current Sample ($n$ = 114) | |
|---|---|---|
| | Mean | SD |
| Wellbeing (WEMBS) | 42.3 | 10.37 |
| Child Problem Behaviour (NCBR) | 52.41 | 31.84 |
| Parental Locus of Control Total (PLOC) | 114.23 | 15.01 |
| Parental Efficacy | 17.21 | 5.47 |
| Parental Responsibility | 27.58 | 2.42 |
| Child Control | 15.36 | 4.91 |
| Belief in fate | 22.79 | 5.24 |
| Parental Control | 31.29 | 5.89 |

Table 2.3 illustrates the mean and SD for all the mothers across the measures and the individual subscales with the PLOC. These main measures were then explored across the diagnostic groups; the means and SD for parental LOC, wellbeing, and child problem behaviour are shown in Table 2.4. There was little variance between scores of total PLOC and wellbeing across diagnoses groups. However, group means indicated higher levels of problem behaviour reported within the ASD and ID (no aetiology) groups, the lowest level of reported problem behaviour was reported within the Down syndrome and brain injury groups (*see* Table 2.4).

**Table 2.4: Means and standard deviations for all variables across relevant groups**

| Current sample ($n$ = 114) | | | | | | |
|---|---|---|---|---|---|---|
| | ASD[1] | ID[2] | DS[3] | Other[4] | Injury[6] | CD[7] |
| Parental locus of control | 113.4 (15.6) | 120.5 (15.6) | 107.9 (11.1) | 124.7 (13.9) | 110 (11.2) | 116.4 (15.9) |
| Child Problem Behaviour | 65.8 (28.8) | 67 (32.1) | 27.2 (18.8) | 59.1 (28.5) | 18.7 (15.5) | 51.9 (34) |
| Parental subjective wellbeing | 42.9 (10.5) | 40.7 (7.2) | 44.2 (8.9) | 39.2 (11.2) | 47.7 (10.6) | 39.7 (12.3) |

ASD[1] = Autism Spectrum Disorder, ID[2] = Intellectual Disorder, DS[3] = Down Syndrome, Other[4] = Other Syndromes, Injury[6] = Birth Brain Injury, CD[7] = Chromosomal Disorder

### *3.2 Correlational Analysis*

Correlations run with bootstrapping (n = 1000) were used to determine the associations between the demographic, child, and locus of control variables and the wellbeing measures (see Table 2.5). Child diagnosis or level of intellectual disability did correlate with parental wellbeing.

**Table 2.5: Correlational relationship between variables**

**Correlations**

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|
| 1. Wellbeing | 1 | | | | | | | | | |
| 2. Parent Efficacy | -.49** | 1 | | | | | | | | |
| 3. Parent Responsibility | .2* | -.16 | 1 | | | | | | | |
| 4. Child Control | -.52** | .38** | -.09 | 1 | | | | | | |
| 5. Belief in Fate | -0.18 | .35** | .02 | .13 | 1 | | | | | |
| 6. Parental Control | -.48** | .43** | -.09 | .56** | .09 | 1 | | | | |
| 7. Problem Behaviour | -.42** | .41** | -.09 | .35** | .11 | .44** | 1 | | | |
| 8. Employment | .01 | -.14 | .22* | .09 | -.11 | .003 | .02 | 1 | | |
| 9. Diagnosis | -0.12 | .17 | -.01 | .01 | .05 | -.02 | -.23* | .05 | 1 | |
| 10. Level of ID | 0.06 | .04 | .08 | .19* | -.09 | .001 | .02 | -.03 | -.04 | 1 |

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table 2.6 shows the significant correlations with confidence intervals of the proposed mediators, four subscales of PLOC were shown to have a significant relationship with wellbeing. In particular, child control, parent control and parental efficacy were strongly related to both wellbeing and child problem behaviour. Parental responsibility showed a smaller relationship with wellbeing, and was not related to behaviour. These subscales had a negative relationship with wellbeing and a positive relationship with problem behaviour, which may indicate that these subscales indirectly intervene with the effect of problem behaviour on parental wellbeing.

**Table 2.6: Pearson's r and BCa 95% confidence intervals for significant correlations**

| | | | BCa 95% Confidence Intervals | |
|---|---|---|---|---|
| | r | p* | Lower | Upper |
| Wellbeing * Parental Efficacy | -.499 | <.0001 | -.626 | -.356 |
| * Parental Responsibility | .203 | .031 | .009 | .383 |
| * Child Control | -.524 | <.0001 | -.653 | -.374 |
| * Parental Control | -.482 | <.0001 | -.608 | -.331 |
| * Problem Behaviour | -.418 | <.0001 | -.555 | -.249 |
| Problem Behaviour * Parent Efficacy | .408 | <.0001 | .216 | .555 |
| * Child Control | .346 | <.0001 | .200 | .495 |
| * Parental Control | .444 | <.0001 | .285 | .584 |

*BCa, bias corrected and accelerated; 1000 bootstrap samples, r = pearson's r, p* < .0005 level for Type 1 error*

*3.3 Mediation Analysis*

There was a significant indirect effect of child problem behaviour on parental wellbeing through parental total locus of control, $b$ = -.072, BCa CI [-.114, -.041]. This represents a medium effect, $k^2$ = .219, 95% BCa CI [.133, .323]. This indicates that that child problem behaviour has an indirect effect on parental wellbeing through overall parental locus of control. However, previous correlations indicate variance in the level of relationship between parental wellbeing and the individual PLOC subdomains. Further mediation analyses were conducted to investigate this further.

Table 2.7 shows the direct versus indirect effects of the proposed mediators on the studied outcomes. The direct effect of child problem behaviour was non-significant when the proposed mediators were included in the model. In this case, the introduction of mediators allowed for a total of 39% of variance to be explained in wellbeing ($F(4,109)=17.73$, $p<.0001$, $r^2 = .394$). The individual indirect effects are shown in Table 2.7. In the mediation model used, the bootstrapped values of the 95% confidence interval that do not contain 0 between their lower and upper limits are considered to be significant mediators (Preacher and Hayes, 2008).

It can be seen that child problem behaviour indirectly influences parental wellbeing, to a significant level, through its effects on both child control and parent efficacy. Parental control was not shown to uniquely mediate this relationship when considered in the multiple mediator model.

**Table 2.7: Mediation effects of multiple mediators on the relationship between parental wellbeing and child problem behaviour: Total, Direct and Indirect effects**

| | **Mediator** | **Products of Coefficients** | | | | **Bootstrapping 95% BCa Confidence Intervals** | |
|---|---|---|---|---|---|---|---|
| | | Point estimate | SE | t | p | Lower | Upper |
| Total | | -.135 | .028 | -4.81 | <.0001 | -.191 | -.079 |
| Direct | | -.408 | .028 | -1.72 | .087 | -.105 | .007 |
| Indirect (mediation) | Child Control | -.031 | .014 | | | -.062 | -.008 |
| | Parental Control | -.023 | .016 | | | -.059 | .005 |
| | Parent Efficacy | -.033 | .016 | | | -.071 | -.008 |
| | Total | -.086 | .021 | | | -.136 | -.052 |

*95% bias corrected and accelerated confidence intervals, based on 5000 bootstrap samples*

## 4. Discussion

In a broad sample of mother's of children with an ID/DD, including families who attended specialist psychological ID services and families who did not, the combination of several locus of control sub-domains, child problem behaviour, and parental wellbeing were found to be related to each other in theoretically predictable ways. The mother's increased perception of their child controlling their life (child control), feeling less control over their child's behaviour (parental control), and the lower levels of parental efficacy were related to the higher levels of child behavioural problems and lower levels of self-reported maternal wellbeing. These findings are broadly in agreement with previous research; Lloyd & Hastings (2009b) showed a strongly significant relationship between PLOC sub-domains (child control, parental control, and parental efficacy) and measures of stress and depression. A significant relationship for anxiety was shown for both child control and parent control (Lloyd & Hastings, 2009b). Similarly, child control predicted maternal depression and stress, while parental control predicted anxiety, which in combination with the current findings indicate that these sub-domains play an integral role in parental coping, as expressed through their mental health and wellbeing.

The initial mediation analysis confirms that parental LOC mediated the relationship between child problem behaviour and wellbeing, which reflects previous findings of a relationship between higher levels of behavioural problems and an external locus of control (Hageskull *et al.*, 2001; Hassall *et al*., 2005; Jones & Passey, 2005; Lloyd & Hastings, 2009b). This finding was expected, however, in the current study the roles of the sub-domains were of greater interest. The further mediation analyses which explored this relationship indicated the sub-scales of child control and parental efficacy significantly mediate the relationship between child problem behaviour and parental wellbeing. This mediation suggests that the combined parental cognitions and appraisals of their child's behaviour; how they made sense of their child's problem behaviour, affected the parents subjective feelings of wellbeing rather than the actual level of behaviour experienced. This finding builds on Lloyd and Hastings (2009b) indications of the predictive relationship of these factors on parental coping and mental health and is in line with research which highlighted that attributions of responsibility of child behaviour predicted maternal emotions and responses to the children (Chavira, Lopez, Blacher, & Shapiro, 2000). That is; mothers of children with DD who judged their children as responsible for their problem behaviours were more likely to experience negative emotional reactions and to respond with harsh or aggressive disciplinary methods (Chavira *et al*., 2000).

It is interesting to note that despite the moderate relationship between parental control and the two variables; child control and parental efficacy, parental control did not mediate the relationship

between child behaviour and wellbeing. Parental control or a parents feeling less able to control their child, has previously been non-directionally associated with aggressive behaviour in child with ID (Hagekull *et al.*, 2001), maternal stress (Hassall *et al*., 2005), and has predicted maternal anxiety, but not maternal depression (Lloyd & Hastings, 2009). It may be, that by tapping into maternal depression, parenting-efficacy, or parental self-esteem (Lloyd & Hastings, 2009b; Ohan *et al*, 2000), child control and parental efficacy capture elements of wellbeing and problem behaviour. Certainly PLOC and parenting self-esteem have shown some points of conceptual overlap between these (Hassall *et* al., 2005), and there may be an argument for locus of control to be viewed as one expression of the concept of 'self efficacy' (Bandura, 1982). Previous research has indicated that general self-efficacy mediated the effect of child behaviour problems on anxiety and depression in mothers of children with ASD (Hastings & Brown, 2002), that and therefore it is plausible to presuppose that it would have a similar effect on wellbeing. These findings support the view that differences between parental wellbeing and coping are influenced by more than just external factors or situational factors; alternatively there is an internal cognitive attribution process which mediates the parental experience (Abbeduto *et al.*, 2004; Cahill & Glidden, 1996; Goodley & Tregaskis, 2006; Schieve *et al*., 2007); and the importance of cognitive attributions and feeling of control or self-efficacy that may be more significant in predicting your wellbeing and coping, even in light of child behaviour problems.

### *4.1 Clinical Implications*

The findings of child control and parental-efficacy mediation of the relationship between child problem behaviour and parental wellbeing indicate that it would be useful for professionals working with mothers of children with ID or DD to be aware of their cognitive attributions and it illustrates that the way in which parents perceive and make sense of their situation is vitally important. It may be useful to consider PLOC, in particular the subscales of child control and parental-efficacy, as a further assessment tool for parents in which it may be an indicator for parents who may already or may be at risk of experiencing low levels of wellbeing, increased anxiety, depression and the implication of poorer adjustment over time (Lloyd & Hastings, 2009b). Therefore, this could be helpful to enable early identification of families who are likely to struggle, and to allow early intervention and support before more major difficulties arise.

It is important for practitioners to be aware of individual parent's beliefs when working with families, as it may inform and impact the areas of difficulty for parents. In particular, considering the influence of parent's beliefs around their own control of their child's behaviour and their child's control, their belief of parental efficacy, and feeling dominated by caring for their child. It is important to be aware of these individual appraisals, as each one may result in varying problems and require different approaches and considerations. For example, being aware of a parent's belief

that they have no control over their child behaviour and is an ineffective parent may make it more difficult for that parent to implement a behavioural management strategy and benefit from social support; as the relationship between social support and parental stress has been shown to be mediated by locus of control (Hassall *et* al., 2005). Interventions which may help parents adjust their beliefs and cognitive appraisals may be helpful, in particular a formal group setting may be a powerful way of normalising and for parents to check some of their beliefs with other parents or carers. Interventions which empower parents, allow them to develop their parental efficacy should be encouraged.

### *4.7 Limitations of the study*

The current study relied solely on parent report measures and parental perceptions of their child and their functioning. It may have been useful to use an objective measure of child level of functioning, such as the Vineland Adaptive Behaviour Scales (Sparrow, Cicchetti, & Balla, 2005) or Adaptive Behaviour Assessment System (ABAS-II; Harrison & Oakland, 2003) to compliment or confirm these parental estimations. Similarly, comparison of parent and independent ratings of child behaviour would have been informative, as this may have revealed any discrepancy between perceived and actual levels of stressors. Due to the nature of the study, participants were self-selecting and it was not possible to verify whether their child met the criteria outlined in the study or not. However, this is a common selection method used in DD research (Emerson *et al*., 2006).

The current study did not measure the time since the mothers or families received a diagnosis, and therefore the important influence of this factor could not be considered in the current findings (Aarons & Gittens, 1992; MacDermott *et al*., 2006). Although this study attempted to include some demographic variables, it is important to assess these findings within the wider context of family demographic and environmental factors (Olsson & Hwang, 2008). This study did not account for financial strain, family deprivation, or broader socio-economic adversity, which is vital in considering the wider social context in which families operate. Similarly, the study did not gather information relating to the amount of social support received by mothers or families, or its' relationship with wellbeing and locus of control; for example LOC has been shown to mediate the relationship between social support received and stress for mother of children with ID/DD (Hassall *et* al., 2005). Therefore, although this study highlights some important factors implicated in wellbeing, clearly the issues influencing parental wellbeing in this population are complex and extend beyond cognitive factors. Further research is required to further reveal these factors and the extent of their impact.

Lastly, although efforts were made to encourage the recruitment of fathers in this population, they

still made up a very small proportion of the sample and therefore could not be added to the overall study. This may be due to fathers not identifying themselves as 'caregivers' or primary caregivers, or it may be that mothers tend to be more involved with the parent organisations used for the recruitment of participants. The literature indicates differences in coping and rates of depression or stress between mothers and fathers of children with ID/DD (Bristol *et al.*, 1988; Hastings *et al.*, 2005; Olsson & Hwang, 2001), therefore, these findings cannot be generalised to fathers or male primary carers. Psychological research within ID/DD has typically focused on maternal functioning within families (Cuskelly & Gunn, 2006; Emerson, 2003) and there is a long history of difficulties involving fathers in ID/DD research (Ballard *et al*., 1997; Herbert & Carpenter, 1994; West, 2000). This may be due to the lack of consensus of how a fathers role is defined within the literature (MacDonald & Hastings, 2010), or fathers apparent lack of availability to research due to daily practicalities (McConkey, 1994), or the emphasis in research on biological fathers or fathers within two-parent families (Palm & Fagan, 2008), as there is little research including nonresident fathers of children with ID/DD (Shandra *et al*., 2008).

Research would benefit from more targeted sample of biological and non-biological fathers within families and nonresident fathers, this restriction of the definition of fatherhood limits insights about other fathers; e.g. single fathers, non-resident fathers, step- and adoptive fathers, gay fathers (Parette, Meadan, & Doubet, 2010). It is critical to conduct research that includes more diverse participants rather than convenience sampling to increase representativeness and reflect societal changes (Dyer et al., 2009; MacDonald & Hastings, 2010), adopting a gender differentiated approach, acknowledging needs of fathers and mother may differ different, and focus more research explicitly on male caregivers and actively engaging with men or fathers (MacDonald & Hastings, 2010; Potter & Carpenter, 2008; Potter & Olley, 2012). This approach may benefit from the use of current information and communication technologies (e.g., discussion forums, blogs, information websites), using varied methods of research (i.e., interviews, focus groups, longitudinal) to allow triangulation of data and thereby prevented in-depth understanding of the "voices" of fathers (Parette, Meadan, & Doubet, 2010). Furthermore, personal invitations to fathers for participation, in activities flexibility in scheduling and data collection to accommodate fathers who work outside the home (Parette, Meadan, & Doubet, 2010).

## 5. Conclusion

This research illustrates that maternal attributions impact their overall feeling of wellbeing, in particular their estimations and attributions relating to their own ability and impact as a parent, and their feeling of control over their own life. Furthermore, these cognitive attributions of child control

and parental-efficacy mediate the relationship between child problem behaviour and maternal wellbeing. This study builds on the understanding of parent wellbeing, however further research with more extensive modelling of maternal and paternal attributions while considering social and family dynamics within this complex population is required.

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## Appendix 1: Journal of Applied Research in Intellectual Disabilities

### 1. GENERAL

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit http://authorservices.wiley.com/bauthor/ for further information on the preparation and submission of articles.

All manuscripts must be submitted solely to this journal and not published, in press, or submitted elsewhere.

### 2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

#### 2.1 Authorship and Acknowledgements

**Authorship:** Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

**Acknowledgements:** Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

**2.2 Ethical Approvals**

Research involving human participants will only be pubished if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.

All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

**2.3 Clinical Trials**

Clinical trials should be reported using the CONSORT guidelines available at www.consort-statement.org. A CONSORT checklist should also be included in the submission material (www.consort-statement.org).

The *Journal of Applied Research in Intellectual Disabilities* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: www.clinicaltrials.org, www.isrctn.org. The clinical trial registration number and name of the trial register will then be published with the paper.

**2.4 Conflict of Interest and Source of Funding**

**Conflict of Interest**: Authors are required to disclose any possible conflict of interest. These include financial (for example patent ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading.

The *Journal of Applied Research in Intellectual Disabilities* requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflict of interest noted. As of 1st March 2007, this information is a requirement for all manuscripts submitted to the journal and will be published in a highlighted box on the title page of the article. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of the manuscript.

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Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing.

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**4.2 Blinded Review**

All articles submitted to the journal are assessed by at least two anonymous reviewers with

expertise in that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.

## 5. MANUSCRIPT TYPES ACCEPTED

***Original Articles, Review Articles, Brief Reports, Book Reviews*** and ***Letters to the Editor*** are accepted. ***Theoretical Papers*** are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

## 6. MANUSCRIPT FORMAT AND STRUCTURE

### 6.1 Format

**Language:** The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

### 6.2 Structure

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

***Cover Page:*** A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

***Running Title:*** A short title of not more than fifty characters, including spaces, should be provided.

***Keywords***: Up to six key words to aid indexing should also be provided.

***Main Text:*** All papers should be divided into a structured abstract (150 words) and the main text with appropriate sub headings. A structured abstract should be given at the beginning of each article, incorporating the following headings: Background, Materials and Methods, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. The text should then proceed through sections of Introduction, Materials and Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file.

***Style:*** Manuscripts should be formatted with a wide margin and double spaced. Include all parts of

the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:

-Include all figure legends, and tables with their legends if available.

-Do not use the carriage return (enter) at the end of lines within a paragraph.

-Turn the hyphenation option off.

-In the cover email, specify any special characters used to represent non-keyboard characters.

-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).

-Use a tab, not spaces, to separate data points in tables.

-If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

**6.3 References**

The reference list should be in alphabetic order thus:

-Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge University Press, Cambridge.

-McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.

-Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130-145

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al*. 1977). Authors are responsible for the accuracy of their references.

We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.

EndNote reference styles can be searched for here:

http://www.endnote.com/support/enstyles.asp

Reference Manager reference styles can be searched for here:

http://www.refman.com/support/rmstyles.asp

The Editor and Publisher recommend that citation of online published papers and other material should be done via a DOI (digital object identifier), which all reputable online published material should have - see www.doi.org/ for more information. If an author cites anything which does not have a DOI they run the risk of the cited material not being traceable.

### 6.4 Tables, Figures and Figure Legends

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption. Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

**Preparation of Electronic Figures for Publication:** Although low quality images are adequate for review purposes, print publication requires high quality images to prevent the final product being blurred or fuzzy. Submit EPS (line art) or TIFF (halftone/photographs) files only. MS PowerPoint and Word Graphics are unsuitable for printed pictures. Do not use pixel-oriented programmes. Scans (TIFF only) should have a resolution of at least 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size. Please submit the data for figures in black and white or submit a Colour Work Agreement Form. EPS files should be saved with fonts embedded (and with a TIFF preview if possible).

Further information can be obtained at Wiley-Blackwell's guidelines for figures:
http://authorservices.wiley.com/bauthor/illustration.asp.

Check your electronic artwork before submitting it:
http://authorservices.wiley.com/bauthor/eachecklist.asp.

**Permissions:** If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publisher.

**Colour Charges:** It is the policy of the *Journal of Applied Research in Intellectual Disabilities* for authors to pay the full cost for the reproduction of their colour artwork
http://www.blackwellpublishing.com/pdf/SN_Sub2000_X_CoW.pdf

## 7. AFTER ACCEPTANCE

Upon acceptance of a paper for publication, the manuscript will be forwarded to the Production Editor who is responsible for the production of the journal.

### 7.1 Proof Corrections

The corresponding author will receive an e-mail alert containing a link to a website. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF file from this site.
Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following website:
www.adobe.com/products/acrobat/readstep2.html
This will enable the file to be opened, read on screen, and printed out in order for any corrections to be added. Further instructions will be sent with the proof. Proofs will be posted if no e-mail address is available; in your absence, please arrange for a colleague to access your e-mail to retrieve the proofs.

Proofs must be returned to the Production Editor within 3 days of receipt.
As changes to proofs are costly, we ask that you only correct typesetting errors. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately. Other than in exceptional circumstances, all illustrations are retained by the Publisher. Please note that the author is responsible for all statements made in their work, including changes made by the copy editor.

## Appendix 2: American Association on Intellectual and Developmental Disabilities

### Manuscript Submission

*American Journal on Intellectual and Developmental Disability (AJIDD)* uses a Web-based manuscript submission and peer-review system called AllenTrack. Manuscripts should be submitted electronically to ajidd.allentrack.net. Given that all manuscripts will be reviewed anonymously, the author's name and other identifying information should appear only on the cover page. Potentially identifying information in the text should be removed prior to submission. The journal's Editor and Associate Editors oversee manuscript reviews. Once a manuscript is submitted, an Editor-in-Charge is assigned who is responsible for assigning the peer reviewers and deciding on the disposition of all manuscripts (acceptance, rejection, or requests for revision). The initial review process ordinarily takes from 8 to 10 weeks, and revisions are often requested. Once a manuscript is accepted for publication, the remainder of the production process is coordinated by AAIDD's Publications Department (journals@aaidd.org).

Corresponding authors who require assistance in submitting their manuscripts through AllenTrack should contact the editorial office via e-mail at leonard.abbeduto@ucdmc.ucdavis.edu. AllenTrack can convert most word-processing files (e.g., Word, WordPerfect, Text, Postscript, and Rich Text Format).

Before submitting a **manuscript**, please gather the following information:

All Authors

- First Names, Middle Names/Initials, Last Names
- Institution
- Department
- E-mail addresses
- Title and Running Title (you may copy and paste these from your manuscript)
- Abstract (you may copy and paste this from your manuscript)
- Key words
- Manuscript files in Word (doc), WordPerfect (wpd), or Rich Text Format (rtf)
- All tables and figures will have to be provided as either Word or Excel files.

The separate **Cover Page**, Word (doc), WordPerfect (wpd), or Rich Text Format (rtf) should include the following elements:

**CoverPage**

TITLE OF MANUSCRIPT

***(All Authors First Names, Middle Initials [if applicable], Surnames [in order of authorship])***

Corresponding Author:

**Author Name** Highest degree earned, title (if applicable)

Email address: xxxx@xxx.edu

Institutional Affiliation

Departmental Affiliation

Street Address

City, State, Zip, Country

**Second Author Name** Highest degree earned, title (if applicable), affiliation, city, state, zip, country

**Third Author Name** Highest degree earned, title (if applicable), affiliation, city, state, zip, country

***Please provide information for all authors**

**Acknowledgments**
Where was manuscript presented, oral or poster?
Was this manuscript funded? By what entity? Grant number(s), if applicable
Thanks for support, if desired

Manuscript files [(Word (doc), WordPerfect (wpd), or Rich Text Format (rtf)] should not contain any identifying information, but should include the following:

Title

Abstract

Key words

Manuscript Text

**Ethical Standards**

All investigations using human participants must have been approved by the human subjects review committee of the author's institution. Submission of a manuscript to *AJIDD* while that paper is under review by another journal is unacceptable. Presentation of a manuscript in electronic form on the Internet is considered to constitute publication and may be grounds for rejection of the paper by this journal.

**Form**

Manuscripts should be prepared in accordance with the 2009 *Publication Manual of the American Psychological Association* (APA, 6th edition). All sections of the manuscript (including quotations, references, and tables) should be double-spaced with a 1-inch margin on all sides. References must be in APA style. An abstract of no more than 120 words is required. The preferred length of manuscripts is 20–30 typed pages or less, including references, but somewhat greater length may be accepted, depend-

ing on the complexity and importance of the research. Brief reports are generally 5–10 manuscript pages and contain a limited number of findings in comparison to research articles. Authors are encouraged to submit shorter, more concise manuscripts.

Any accompanying figures must be submitted as separate files (not embedded in the text) and must be over 200 dpi resolution. It is the authors' responsibility to submit publishable graphic elements. Any graphics that are of a lower resolution than 200 dpi will be rejected. Usually, figures submitted directly from a software application such as Excel are too low quality.

**Abbreviations and Terminology**

Abbreviations should be held to a minimum and spelled out in their first use. The names of groups or experimental conditions are usually not abbreviated. The full names of tests should be given when they are first mentioned, with the common shortened form in parentheses with a citation of the source.

When context makes it clear whether an author is referring to people with intellectual disabilities or when it is otherwise unnecessary to refer to intellectual level or diagnostic category, authors should use the most descriptive generic terms, such as children, students, or people or individuals (not persons), without using qualifiers such as "with intellectual disabilities," "with handicaps," or "with developmental disabilities." The journal adheres to AAIDD's use of people-first language. Prepositional constructions such as "students with intellectual disabilities" or "individuals who have intellectual disabilities" are preferred over adjectival constructions such as "intellectual disabilities people," except when clear communication dictates occasional use of adjectival designations. Because "normal" has multiple meanings and may inappropriately imply abnormal where it is not applied, this word should not be used. Instead, more operationally descriptive terms such as *intellectually* average pupils or *typical* participants should be used.

**Numerical and Illustrative Presentations**

The metric system should be used for all expressions of linear measures, weight, and volume. Tables and figures should be kept to a minimum. Information should be presented only once—whether in the text or in a table or figure. For this reason, short tables may be deleted or combined into larger ones during the copyediting process. Tables must be created using the table function of a word-processing program. All columns should be provided with headings. AllenTrack accepts figures in JPEG, TIFF, GIF, EPS, PDF, or Postscript formats with a minimum requirement of 200 dpi. Figure captions should be included in the manuscript text file, but other types of lettering may appear on the figures themselves. All such lettering should be of professional quality and large enough to withstand a reduction of approximately 50%. Release forms (signed, dated, and witnessed) must accompany photographs of human subjects. Care should be taken to conceal the identity of persons in such photographs. Authors must also secure permission to use any copyrighted tables or figures.

**Footnotes**

Content footnotes are not used. An author note can be used to (a) acknowledge grant support or help in carrying out the research or in preparation of the manuscript, (b) noting change in affiliation of an author, or (c) stating the availability of supplementary information.

## Appendix 3: Systematic Review Protocol

Based on York University's Centre for Reviews and Dissemination Guidance for undertaking reviews in healthcare

**Background**

(I) Established evidence base that caring full-time for a child with disabilities impacts on psychological outcomes, such as; stress, adjustment, mental health, and wellbeing.

(II) There is a growing evidence base for the use of mindfulness as an effective intervention for stress and increases mental well-being.

(III) Exploration of mindfulness-based interventions for this population would be clinically useful, as this would inform possible future service input with families and parents of children with disabilities.

(IV) There is little research relating to the use of mindfulness-based interventions for parents of children with disabilities.

Previous Similar Reviews:

A systematic review of mindfulness interventions for individuals with developmental disabilities (Hwang & Kearney, 2013).

A practitioner review of stress interventions for parents of children with intellectual disabilities (Hastings & Beck, 2004). This review focused on Cognitive Behavioural Therapy (CBT) based group interventions.

A review of 'third-wave' approaches for parents of children with disabilities (Whittingham, 2014). This review focuses on mindfulness and acceptance interventions and their impact on child and/or parental adjustment and reviews four studies found in the literature.

There are currently no systematic reviews focusing on the area of the impact of mindfulness-based interventions on the psychological outcomes for parents of children with disabilities.

**Review Question**

What is the impact or effectiveness of mindfulness-based interventions on the psychological

outcomes (e.g. stress, depression, mental health, and well-being) of parents who have a child with a disability?

**Eligibility Criteria**

1. Published case studies, small studies, controlled studies, non-control studies, quasi-experimental studies
2. All types of study design
3. Mindfulness-Based approaches and experience of parenting, including rating of child behaviour, investigated
4. The relationship or effectiveness of mindfulness-based approaches and parental psychological outcomes investigated
5. Full-text available
6. All dates were included

**Population**

- Parents, and family or primary carers
- At least one child with a physical, intellectual or developmental disability

**Outcomes**

Parent and family psychological outcomes, including:

- Well-being
- adjustment/adaption
- stress
- mental health (e.g. depression or anxiety)
- coping (illustrated through parent report or child behaviour)

**Planned Search Strategy**

Keyword searches of online databases (Embase, Medline, Psycharticles, Psychinfo, CINAHL+, ERIC, ASSIA, and web of knowledge), using search terms parent; parental; mother; father; carer; mindfulness; disab*

**Study Selection**

1. Abstracts screened to detect whether studies meet eligibility criteria
2. Full-texts of remaining studies screened to find whether they meet eligibility criteria
3. Final selection of studies included in the methodological appraisal and analysis

**Data Extraction**

1. Research question
2. Study design
3. Population(s)/sample(s) included

4. Measures used
5. Analyses
6. Generalisability of findings

**Quality Assessment**

- Specific criteria for each dimension
- Scoring categories of: well covered; adequately addressed; poorly addressed; not addressed/not reported; not applicable
- Overall assessment of study to reduce bias and increase transparency (+++, ++, +, and -)

**Data Synthesis**

- Summary of individual study findings and characteristics, using data from standardised data extraction form
- Overall rating for each of the dimensions identified
- Overall summary of state of the literature in this area
- Limitations of available literature
- Areas identified for future research

**Dissemination**

- Chapter in doctoral thesis and portfolio
- Submission for publication

## Appendix 4: Systematic Review Quality Criteria

**1. Research question and objectives**

1.1 The study addresses an appropriate and clearly focused question, drawn from a theoretical model or previous research.

| | |
|---|---|
| Well covered = 3 | |
| Adequately addressed = 2 | |
| Poorly addressed = 1 | |
| Not addressed/not reported = 0 | |
| Not applicable = 0 | |
| Other comments | |

**2. Sampling**

2.1 The characteristics of the participants are representative of the group being studied.

| | |
|---|---|
| Well covered = 3 | |
| Adequately addressed = 2 | |
| Poorly addressed = 1 | |
| Not addressed/not reported = 0 | |
| Not applicable = 0 | |
| Other comments | |

2.2 The study indicates how many of the people asked to take part did so, in each of the groups studied. Also, if applicable, how many dropped out.

| | |
|---|---|
| Well covered = 3 | |
| Adequately addressed = 2 | |
| Poorly addressed = 1 | |
| Not addressed/not reported = 0 | |
| Not applicable = 0 | |
| Other comments | |

2.3 The exact nature and severity of the child's disability/impairment and its impact on every day family and child functioning is described.

| | |
|---|---|
| Well covered = 3 | |
| Adequately addressed = 2 | |
| Poorly addressed = 1 | |
| Not addressed/not reported = 0 | |
| Not applicable = 0 | |
| Other comments | |

**3. Design and method**

3.1 The constructs/variables under investigation are clearly defined and operationalised.

| | |
|---|---|
| Well covered = 3 | |
| Adequately addressed = 2 | |
| Poorly addressed = 1 | |
| Not addressed/not reported = 0 | |
| Not applicable = 0 | |
| Other comments | |

3.2 Variable measurement method is appropriate and demonstrates validity and reliability.

| | |
|---|---|
| Well covered = 3 | |
| Adequately addressed = 2 | |
| Poorly addressed = 1 | |
| Not addressed/not reported = 0 | |
| Not applicable = 0 | |
| Other comments | |

**6. Generalisability**

6.1 The findings could be generalised to similar populations.

| | |
|---|---|
| Well covered<br>= 3 | |
| Adequately addressed<br>= 2 | |
| Poorly addressed<br>= 1 | |
| Not addressed/not reported<br>= 0 | |
| Not applicable<br>= 0 | |
| Other comments | |

**7. Overall assessment of study**

7.1 A judgement of the overall quality of the study.

| | |
|---|---|
| ++ Good to excellent<br>= 3 | |
| + Adequate to good<br>= 2 | |
| - Poor to adequate<br>=1 | |

## Appendix 5: Participant Information Sheet and Consent Form

Dear Parent / Carer

I work with children and young people with learning disabilities and developmental disabilities and their families. These are terms you may be familiar with, although these sometimes can be confusing. Learning Disability is described by Mencap as a reduced intellectual ability and difficulty with everyday activities, for example household tasks, socialising or managing money, and these difficulties are life-long. Children who have a Learning Disability may often receive a diagnosis of a developmental disability. This can further impact on the kind of support they and their families need in their day-to-day life.

It is common for families and caregivers to respond in different ways to having children with learning disabilities, it can be a positive experience with many enriching experiences, however, it can also bring a number of challenges. There are many parents of children with Learning Disabilities who may struggle with the emotional and practical aspects of caring for their child, some families have had positive experiences.

As part of this project, I would like to look how families and caregivers adapt to having a child with a learning disability and/or a Developmental Disability and how psychologists and other professionals may be able to support this. It is hoped that this research, and further research like it, can help inform how services work with caregivers and families, and the type of support they provide. I would be very grateful if you could complete this survey as part of my research. The research project has had ethical approval from NHS and is being supervised by Dr Helen Downie, Dr Emily Newman, and Dr Dougal Hare at the University of Edinburgh.

We only need one parent or caregiver to complete the survey, usually the primary caregiver. Please direct other parents/carers of children with learning disabilities to it at: https://www.survey.ed.ac.uk/parental_wellbeing.

The survey contains different questions, which should take around 15 minutes to complete in total. There are no right or wrong answers -I am interested in what you think and how you feel. All your answers will be anonymous and you will not be identifiable. If you have concerns that information we are asking for will identify your child or your family, you do not have to provide this information.

Some of the questions might make you feel or think about things that are difficult and/or upsetting.

We recognise that having a child with a learning disability and/or a developmental disability can have both negative and positive aspects. If you want to talk about this or would like some advice about seeking formal support for this, please contact me using the details on the next page. If you are happy to take part and complete the questionnaire, the next page has details about what this will involve, followed by the questions.
Thank you for your time.

Fiona McCrohan
Trainee Clinical Psychologist
Clinical & Health Psychology
School of Health in Social Science
University of Edinburgh
Edinburgh EH8 9AG Email: parental.wellbeing@gmail.com

**Why have I been asked to take part?**
You have asked to take part as you care for a child with a learning disability, with or without a second diagnosis of a developmental disorder (e.g. Autism Spectrum Disorders).

**What will participation involve?**
Taking part in this research will involve answering the questions contained in this booklet and returning your completed questionnaire using the postage paid envelope provided. If you would prefer to complete the questionnaire online, please visit:
https://www.survey.ed.ac.uk/parental_wellbeing

**What will happen to this information?**
The information will be anonymous and will be used only for the purpose of this research. The overall findings will be written up and shared with other researchers and professionals to help ensure that families' needs are better understood. We are not asking for information that could be used to identify you or your family. If you have concerns that information we are asking for will identify your child or your family, you do not have to provide this information.
Questionnaires cannot be withdrawn once submitted, as they will be anonymous and it will be impossible to know which one is yours.

**Do I have to take part?**
No, it is up to you to decide whether or not to take part. You do not have to complete the questionnaires, only complete them if you want to. If you decide to take part you are still free to withdraw at any time and without giving a reason. However, please be aware that due to the

anonymous nature of the information, once fully submitted it will not be possible to identify your individual responses and therefore it will not be possible to remove them. Deciding not to take part or withdrawing from the study will not affect the healthcare that you receive, or your legal rights.

**What are the possible benefits and disadvantages of taking part?**

There are no direct benefits to you taking part in this study, but the results from this study might inform future services working with families of children with learning disabilities and/or Developmental disorders.

However, it is possible that some of the questions may be difficult to answer. If this is the case and you wish to speak to someone please contact the email address below.

**What happens when the study is finished?**

At the end of the research the anonymous data which is collected will be stored within NHS protected computers for up to 5 years. It will be safely destroyed after this time.

**Will my taking part in the study be kept confidential?**

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage.

**What will happen to the results of the study?**

The study will be written up as an academic paper with the aim of being published in an academic journal. It will be highlighted to Child and Adolescent Mental Health Services and findings will be made available to participants through the forum in which you were recruited.

**Who has reviewed the study?**

The study proposal has been reviewed by NHS Lothian and the NHS ethics boards and University of Edinburgh. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. A favourable ethical opinion has been obtained from Greater Manchester West REC. NHS management approval has also been obtained.

**What if I want to talk to someone?**

If you have any questions about the study or would like help in finding out about further support, you can contact me by email: parental.wellbeing@gmail.com

If you wish to make a complaint about the study please contact NHS Lothian:

NHS Lothian Complaints Team

2nd Floor

Waverley Gate

2 -4 Waterloo Place

Edinburgh

EH1 3EG

Tel: 0131 465 5708 complaints.team@nhslothian.scot.nhs.uk.

## Appendix 6: Participant Advertisement

Dear Parent/Caregiver

**You are invited to take part in research** to look how families and caregivers adapt to having a child with a learning disability and/or a Developmental Disability. It is common for families and caregivers to respond in different ways to having children with learning disabilities, it can be a positive experience with many enriching experiences, however, it can also bring a number of challenges. It is hoped that this research, and further research like it, can help inform how services work with caregivers and families, and the type of support they provide.

**What is it?** An online survey containing different questions, which should take around 15 minutes to complete in total.
**Is it anonymous?** Yes. All your answers will be anonymous and you will not be identifiable. If you have concerns that information we are asking for will identify your child or your family, you do not have to provide this information.
**How do I complete it?** We only need one parent or caregiver to complete the survey, usually the primary caregiver. If you would like to take part, please go to:
https://edinburgh.onlinesurveys.ac.uk/parental_wellbeing

If you would like further information, a paper copy of the survey, or have a general enquiry please contact parental.wellbeing@gmail.com.
Thank you.

Fiona McCrohan
Trainee Clinical Psychologist, NHS Lothian

## Appendix 7: Ethics Letter of Approval

1

NHS
Health Research Authority
National Research Ethics Service

**NRES Committee North West - Greater Manchester Wes**
HRA NRES Centre Mancheste
Barlow House
3rd Floo
4 Minshull Stree
Mancheste
M1 3D2

Telephone: 0161 625 781
Facsimile: 0161 625 729

22 May 2014

Ms Fiona McCrohan
Trainee Clinical Psychologist
NHS Lothian
Clinical Psychology
Teviot Place
Edinburgh
EH8 9AG

Dear Ms McCrohan

| | |
|---|---|
| **Study title:** | **The effect of Locus of Control on parental well-being in parents of children with a Learning Disability/Developmental Disorder: a CAMHS and non-CAMHS population comparison** |
| **REC reference:** | **14/NW/0150** |
| **Protocol number:** | **Protocol_1** |
| **IRAS project ID:** | **142542** |

Thank you for your email of 21 May. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 10 March 2014

**Documents received**

The documents received were as follows:

| *Document* | *Version* | *Date* |
|---|---|---|
| Participant Information Sheet | 2.2 | 30 April 2014 |
| Advert | | |

**Approved documents**

The final list of approved documentation for the study is therefore as follows:

| *Document* | *Version* | *Date* |
|---|---|---|
| Evidence of insurance or indemnity | | 25 June 2013 |
| Investigator CV | Newman | |
| Investigator CV | McCrohan | |
| Participant Information Sheet | 2.2 | 30 April 2014 |

2

| | | |
|---|---|---|
| Protocol | 1.0 | 17 December 2013 |
| Questionnaire: Parental Locus of Control Scale | | |
| Questionnaire: Sheffield Learning Disability Outcome Measure | | |
| Questionnaire: Warwick-Edinburgh Mental Wellbeing Scale | | |
| Questionnaire: The Nisonger Child Behaviour Rating Form | | |
| Questionnaire: Problem Behavior | | |
| Questionnaire: Participant Information | | |
| REC application | 3.5 | 26 February 2014 |

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

**14/NW/0150** **Please quote this number on all correspondence**

Yours sincerely

**Mrs Carol Ebenezer**
**REC Manager**

E-mail: nrescommittee.northwest-gmwest@nhs.net

*Copy to:* *Charlotte Clarke, University of Edinburgh*
*Ms Karen Maitland, NHS Lothian - Research Governance Manager*

## Appendix 8: Section I – Participant Information

As part of the study, it is useful to gather some background information about you and the child you care for. All information provided is non-identifiable and confidential. Please circle your answers and try to answer all questions to the best of your knowledge. If you are unsure or would like further information in relation to any question please contact us at parental.wellbeing@gmail.com.

1. Are you the primary caregiver to a child with a Learning Disability/Developmental Disability?
   YES NO
2. What is your current age?

3. Are you currently employed?
   Full-time Part-time Not employed

4. What is your current relationship status?
   Single Live with Partner Married Divorced Widowed

5. What is the child's age that you care for?

6. What diagnosis of a syndrome (if any) does your child have?
   a) Downs Syndrome
   b) Fragile X syndrome
   c) Cri du chat syndrome
   d) Prader-Willi Syndrome
   e) Other. Please specify: ……
   d) None identified/reported

7. What diagnosis has your child received? (Circle as many as apply)
   a) Autism Spectrum Disorder (ASD)
   b) Learning Disability
   c) Attention Deficit Hyperactivity Disorder (ADHD)
   d) Oppositional Defiant Disorder (ODD)
   e) Conduct Disorder (CD)
   f) Obsessive Compulsive Disorder (OCD)
   g) None
   h) Other. Please specify: ……..

8. What level of Learning Disability has your child been diagnosed (measured or estimated)?
   a) Borderline
   b) Mild Learning Disability
   c) Moderate Learning Disability
   d) Severe Learning Disability

9. What medication, if any, is your child currently prescribed? (e.g. Ritalin, Clonidine, etc.)

10. How many children do you have?

11. Are you **currently** involved with Children and Adolescent Mental Health Services?
   a) Outpatient Service
   b) Learning Disability Service
   c) Community Nursing
   d) No Service

12. Have you ever been involved with Child and Adolescent Mental Health Services?
   a) Never involved with a service
   b) Once. How recently, please specify: ……
   c) More Than Once. How recently, please specify: …….

13. Have you ever been involved with Community Nursing?
   a) Never involved with a service

b) Once. How recently, please specify:
c) More Than Once. How recently, please specify:

**Parental Locus Of Control Scale - revised version (PLOC-R)**

Many parents who have a child with special needs believe that particular child has had a special effect on them and on other members of their family. What effect do you believe your child with a disability has had on you and other members of your family? Read each statement and indicate the one response that best describes how much you agree or disagree with each statement using the following answers:

*Note: Items followed by (R) are reverse scored*

| *Parental Efficacy Subscale* | Strongly Disagree | Disagree | Not Sure | Agree | Strongly Agree |
|---|---|---|---|---|---|
| What I do has little effect on my child's behaviour. | 1 | 2 | 3 | 4 | 5 |
| When something goes wrong between me and my child, there is little I can do to correct it. | 1 | 2 | 3 | 4 | 5 |
| If your child throws tantrums no matter what you try, you might as well give up. | 1 | 2 | 3 | 4 | 5 |
| My child usually ends up getting his/her way, so why try? | 1 | 2 | 3 | 4 | 5 |
| No matter how hard a parent tries, some children will never learn to be responsible. | 1 | 2 | 3 | 4 | 5 |
| It is not always wise to expect too much from my child because many things turn out to be a matter of good or bad luck anyway. | 1 | 2 | 3 | 4 | 5 |
| When my child gets angry I can usually deal with him/her if I stay calm. (R) | 5 | 4 | 3 | 2 | 1 |
| When I set expectations for my child, I am almost certain that I can help him/her meet them. (R) | 5 | 4 | 3 | 2 | 1 |

| *Parental Responsibility Subscale* | Strongly Disagree | Disagree | Not Sure | Agree | Strongly Agree |
|---|---|---|---|---|---|
| When my child is well-behaved, it is because he/she is responding to my efforts. | 1 | 2 | 3 | 4 | 5 |
| Parents who can't get their children to listen to them don't understand how to get along with their children. | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| My child's behaviour problems are no one's fault but my own. (R) | 5 | 4 | 3 | 2 | 1 |
| Capable people who fail to become good parents have not followed through on their opportunities. (R) | 5 | 4 | 3 | 2 | 1 |
| Children's behaviour problems are often due to mistakes their parents make. | 1 | 2 | 3 | 4 | 5 |
| Parents whose children make them feel helpless just aren't using the best parenting techniques. (R) | 5 | 4 | 3 | 2 | 1 |
| Most children's behaviour problems would not have developed if their parents had had better parenting skills. | 1 | 2 | 3 | 4 | 5 |
| I am responsible for my child's behaviour. (R) | 5 | 4 | 3 | 2 | 1 |
| The misfortunes and successes I have had as a parent are a direct result of my own behaviour. | 1 | 2 | 3 | 4 | 5 |

| ***Child Control of Parent's Life Subscale*** | **Strongly Disagree** | **Disagree** | **Not Sure** | **Agree** | **Strongly Agree** |
|---|---|---|---|---|---|
| My life is chiefly controlled by my child. | 1 | 2 | 3 | 4 | 5 |
| My child does not control my life. (R) | 5 | 4 | 3 | 2 | 1 |
| My child influences the number of friends I have. | 1 | 2 | 3 | 4 | 5 |
| It is easy for me to avoid and function independently of my child's attempts to have control over me. (R) | 5 | 4 | 3 | 2 | 1 |
| I feel like what happens in my life is mostly determined by my child | 1 | 2 | 3 | 4 | 5 |

| ***Parental Belief in Fate/Chance Subscale*** | **Strongly Disagree** | **Disagree** | **Not Sure** | **Agree** | **Strongly Agree** |
|---|---|---|---|---|---|
| Being a good parent often depends on being lucky enough to have a good child. | 1 | 2 | 3 | 4 | 5 |
| I'm just one of those lucky parents who happened to have a good child. | 1 | 2 | 3 | 4 | 5 |
| I have often found that when it comes to my children, what is going to happen will happen. | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| Fate was kind to me—if I had had a bad child I don't know what I would have done. | 1 | 2 | 3 | 4 | 5 |
| Success in dealing with children seems to be more a matter of the child's moods and feelings at the time rather than one's own actions. | 1 | 2 | 3 | 4 | 5 |
| Neither my child nor myself is responsible for his/her behaviour. | 1 | 2 | 3 | 4 | 5 |
| In order to have my plans work, I make sure they fit in with the desires of my child. | 1 | 2 | 3 | 4 | 5 |
| Most parents don't realise the extent to which how their children turn out is influenced by accidental happenings. | 1 | 2 | 3 | 4 | 5 |
| Heredity plays the major role in determining a child's personality. | 1 | 2 | 3 | 4 | 5 |

| ***Parental Control of Child's Behaviour Subscale*** | **Strongly Disagree** | **Disagree** | **Not Sure** | **Agree** | **Strongly Agree** |
|---|---|---|---|---|---|
| I always feel in control when it comes to my child. (R) | 5 | 4 | 3 | 2 | 1 |
| My child's behaviour is something more than I can handle. | 1 | 2 | 3 | 4 | 5 |
| Sometimes I feel that my child's behaviour is hopeless. | 1 | 2 | 3 | 4 | 5 |
| It is often easier to let my child have his/her way than to put up with a tantrum. | 1 | 2 | 3 | 4 | 5 |
| I find that sometimes my child can get me to do things I really did not want to do. | 1 | 2 | 3 | 4 | 5 |
| My child often behaves in a manner very different from the way I would want him/her to behave. | 1 | 2 | 3 | 4 | 5 |
| Sometimes when I'm tired I let my children do things I normally wouldn't. | 1 | 2 | 3 | 4 | 5 |
| Sometimes I feel that I do not have enough control over the direction my life is taking. | 1 | 2 | 3 | 4 | 5 |
| I allow my child to get away with things. | 1 | 2 | 3 | 4 | 5 |
| It is not too difficult to change my child's mind about something. (R) | 5 | 4 | 3 | 2 | 1 |

## Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)

Below are some statements about feelings and thoughts. Please tick the box that best describes your experience of each over the last 2 weeks.

| | None of the time | Rarely | Some of the time | Often | All of the time |
|---|---|---|---|---|---|
| I've been feeling optimistic about the future | 1 | 2 | 3 | 4 | 5 |
| I've been feeling useful | 1 | 2 | 3 | 4 | 5 |
| I've been feeling relaxed | 1 | 2 | 3 | 4 | 5 |
| I've been feeling interested in other people | 1 | 2 | 3 | 4 | 5 |
| I've been dealing with problems well | 1 | 2 | 3 | 4 | 5 |
| I've been thinking clearly | 1 | 2 | 3 | 4 | 5 |
| I've been feeling good about myself | 1 | 2 | 3 | 4 | 5 |
| I've been feeling close to other people | 1 | 2 | 3 | 4 | 5 |
| I've been feeling confident | 1 | 2 | 3 | 4 | 5 |
| I've been able to make up my own mind about things | 1 | 2 | 3 | 4 | 5 |
| I've been feeling loved | 1 | 2 | 3 | 4 | 5 |
| I've been interested in new things | 1 | 2 | 3 | 4 | 5 |
| I've been feeling cheerful | 1 | 2 | 3 | 4 | 5 |

*Warwick-Edinburgh Mental Well-being Scale (WEMWBS)*

## The Nisonger Child Behaviour Rating Form

I. Please describe any special circumstances or mediating factors that may have affected the child's behavior in the recent past (the last month or two) or prevented you from making complete ratings.

II. **POSITIVE SOCIAL.** Please describe the child's behavior as it was at home over the last month.

| | IN THE LAST MONTH, THIS CHILD HAS: | Not True [0] | Somewhat or Sometimes True [1] | Very or Often True [2] | Completely or Always True [3] |
|---|---|---|---|---|---|
| 1. | Accepted redirection | • | • | • | • |
| 2. | Expressed ideas clearly | • | • | • | • |
| 3. | Followed rules | • | • | • | • |
| 4. | Initiated positive interactions | • | • | • | • |
| 5. | Participated in group activities | • | • | • | • |
| 6. | Resisted provocation, was tolerant | • | • | • | • |
| 7. | Shared with or helped others | • | • | • | • |
| 8. | Stayed on task | • | • | • | • |
| 9. | Was cheerful or happy | • | • | • | • |
| 10. | Was patient, able to delay | • | • | • | • |

**Developed by M. G. Aman, M. J. Tassé, J. Rojahn, and D. Hammer, 1995.**

III. **PROBLEM BEHAVIOR.** For each item that describes the child's behavior as it was over the last month, circle the:

> 0.... if the behavior **did not** occur or **was not a problem**
> 1.... if the behavior occurred **occasionally** or was a **mild problem**
> 2.... if the behavior occurred **quite often** or was a **moderate problem**
> 3.... if the behavior occurred **a lot** or was a **severe problem**

For each problem that occurred, circle only the score that best describes the behavior.

**PLEASE DO NOT SKIP ANY QUESTIONS. IF YOU DO NOT KNOW THE ANSWER OR HAVE NOT HAD A CHANCE TO OBSERVE THE CHILD FOR A GIVEN TIME, CIRCLE THE ZERO.**

| | | | | |
|---|---|---|---|---|
| 1. Apathetic or unmotivated | 0 | 1 | 2 | 3 |
| 2. Argues with parents, teachers, or other adults | 0 | 1 | 2 | 3 |
| 3. Clings to adults, too dependent | 0 | 1 | 2 | 3 |
| 4. Cruelty or meanness to others | 0 | 1 | 2 | 3 |
| 5. Crying, tearful episodes | 0 | 1 | 2 | 3 |
| 6. Hits or slaps own head, neck, hands, or other body parts | 0 | 1 | 2 | 3 |
| 7. Defiant, challenges adult authority | 0 | 1 | 2 | 3 |
| 8. Knowingly destroys property | 0 | 1 | 2 | 3 |
| 9. Difficulty concentrating | 0 | 1 | 2 | 3 |
| 10. Disobedient | 0 | 1 | 2 | 3 |
| 11. Rocks body or head back and forth repetitively | 0 | 1 | 2 | 3 |
| 12. Doesn't feel guilty after misbehaving | 0 | 1 | 2 | 3 |
| 13. Easily distracted | 0 | 1 | 2 | 3 |
| 14. Easily frustrated | 0 | 1 | 2 | 3 |
| 15. Overly sensitive; feelings easily hurt | 0 | 1 | 2 | 3 |
| 16. Exaggerates abilities or achievements | 0 | 1 | 2 | 3 |
| 17. Explosive, easily angered | 0 | 1 | 2 | 3 |
| 18. Has rituals such as head rolling or floor pacing | 0 | 1 | 2 | 3 |
| 19. Fails to finish things he/she starts | 0 | 1 | 2 | 3 |
| 20. Feelings easily hurt | 0 | 1 | 2 | 3 |
| 21. Feels others are against him/her | 0 | 1 | 2 | 3 |
| 22. Harms self by scratching skin or pulling hair | 0 | 1 | 2 | 3 |
| 23. Feels worthless or inferior | 0 | 1 | 2 | 3 |
| 24. Fidgets, wiggles, or squirms | 0 | 1 | 2 | 3 |
| 25. Shy around others; bashful | 0 | 1 | 2 | 3 |
| 26. Gets in physical fights | 0 | 1 | 2 | 3 |
| 27. Irritable | 0 | 1 | 2 | 3 |
| 28. Repeatedly flaps or waves hands, fingers or objects (such as pieces of string) | 0 | 1 | 2 | 3 |
| 29. Isolates self from others | 0 | 1 | 2 | 3 |
| 30. Lying or cheating | 0 | 1 | 2 | 3 |
| 31. Nervous or tense | 0 | 1 | 2 | 3 |
| 32. Gouges self, puts things in ears, nose, etc., or eats inedible things | 0 | 1 | 2 | 3 |
| 33. Overactive, doesn't sit still | 0 | 1 | 2 | 3 |
| 34. Overly anxious to please others | 0 | 1 | 2 | 3 |
| 35. Overly excited, exuberant | 0 | 1 | 2 | 3 |
| 36. Physically attacks people | 0 | 1 | 2 | 3 |
| 37. Refuses to talk | 0 | 1 | 2 | 3 |
| 38. Repeats the same sound, word, or phrase over and over | 0 | 1 | 2 | 3 |
| 39. Restless, high energy level | 0 | 1 | 2 | 3 |
| 40. Runs away from adults, teachers, or other authority figures | 0 | 1 | 2 | 3 |
| 41. Says no one likes him/her | 0 | 1 | 2 | 3 |
| 42. Secretive, keeps things to self | 0 | 1 | 2 | 3 |
| 43. Repeatedly bites self hard enough to leave tooth marks or break skin | 0 | 1 | 2 | 3 |
| 44. Self-conscious or easily embarrassed | 0 | 1 | 2 | 3 |
| 45. Shifts rapidly from topic to topic when talking | 0 | 1 | 2 | 3 |
| 46. Short attention span | 0 | 1 | 2 | 3 |
| 47. Shy or timid behavior | 0 | 1 | 2 | 3 |
| 48. Steals | 0 | 1 | 2 | 3 |
| 49. Odd repetitive behaviors (e.g., stares, grimaces, rigid postures) | 0 | 1 | 2 | 3 |
| 50. Stubborn, has to do things own way | 0 | 1 | 2 | 3 |
| 51. Sudden changes in mood | 0 | 1 | 2 | 3 |
| 52. Sulks, is silent and moody | 0 | 1 | 2 | 3 |
| 53. Physically harms or hurts self on purpose | 0 | 1 | 2 | 3 |
| 54. Talks back to teacher, parents, or other adults | 0 | 1 | 2 | 3 |
| 55. Talks too much or too loud | 0 | 1 | 2 | 3 |
| 56. Temper tantrums | 0 | 1 | 2 | 3 |
| 57. Threatens people | 0 | 1 | 2 | 3 |
| 58. Threatens to harm self | 0 | 1 | 2 | 3 |
| 59. Engages in meaningless, repetitive body movements | 0 | 1 | 2 | 3 |
| 60. Too fearful or anxious | 0 | 1 | 2 | 3 |
| 61. Underactive, slow | 0 | 1 | 2 | 3 |
| 62. Unhappy or sad | 0 | 1 | 2 | 3 |
| 63. Violates rules | 0 | 1 | 2 | 3 |
| 64. Withdrawn, uninvolved with others | 0 | 1 | 2 | 3 |
| 65. Worrying | 0 | 1 | 2 | 3 |
| 66. Argues with other children or peers | 0 | 1 | 2 | 3 |